

Original Research

Empirical Examination of Caregiving Processes and Outcomes among Adult Siblings of Individuals with Intellectual and Developmental Disabilities

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Abstract

Background: Most individuals with disabilities in the US live in family settings; in some families, siblings are default long-term support providers. Although researchers have explored the roles of parent caregivers, the roles of sibling caregivers need attention.

Methods: In this study, we examined caregiving processes and outcomes among 322 adult sibling support providers (SSPs) with a range of support roles. Adapting a model of caregiving outcomes, we used structural equation modeling to assess relationships among perceived social support, demands, appraisal of caregiving, empowerment, and depression.

Results and Conclusions: Results indicate significant associations among most variables. Appraisal of caregiving emerged as a partial mediator, suggesting that the meaning that SSPs make of their experiences exerts influence on their sense of empowerment and depressive symptoms.



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Keywords

Disabilities; families; adult siblings; social support providers; care; appraisal of caregiving; caregiver empowerment; depressive symptoms

1. Introduction

Most families actively contribute to the lives of family members who have disabilities and demonstrate resilience in doing so [1]. Current estimates suggest that 5.1% of the civilian non-institutionalized U.S. population has intellectual and developmental disabilities [IDDs; The American Community Survey] [2]; 13.1 million of these individuals are adults and 71% of these individuals live with a family caregiver [3] and following the death or incapacity of parents, siblings become caregivers [4, 5].

Swenson and Lakin [6] appraise the economic value of family caregiving at \$400- \$500 billion annually and state that it is the “single most important element” (p. 186) in the integrity of care. They further assert that, without family caregiving, adequate support for individuals with IDD would be unmanageable. Despite the emergence of salutogenic support paradigms, the literature is replete with impacts of care provision for care providers, including financial, temporal, career, health, and family complications of care. Given the benefits of family caregiving to a society with a fundamental concern for the well-being of individuals with IDDs and their families [1], there is a corresponding need to determine how sibling support affects individuals and families, both positively and negatively. Doing so can inform family policy, facilitate workplace practices (including family leave and more), and enable the development of formal and informal family interventions to maximize well-being in situations of sibling care provision.

For the current study, the term *sibling support providers* (SSPs) refers to adult brothers/sisters of individuals with IDDs who provide any form of care and support, and who may or may not reside with their sibling(s). *Caregiving* encompasses the expenditure of time and effort on a daily or intermittent basis and can range from scheduling medical appointments to preparing meals. We are aware of no precise estimates of the number of sibling care providers; however, given that there are about 13.1 million adults with IDDs [2], the number of SSPs may be equivalent or exceed this figure.

Whereas siblings typically support one another in adulthood, siblings of individuals with IDDs may offer a far greater commitment, experience more caregiving demands, and expectations, and report both satisfaction and stress [7]. The above statement can be further understood by applying the concept of “linked lives” which asserts that “people’s lives are lived interdependently and socio-historical influences are expressed through networks of shared relationships” [8]. Thus, life-altering experiences of one family member have life-course implications for other family members, which in this case is SSPs. Unsurprisingly, researchers have identified a plethora of positive and negative physical, psychological, cognitive, and social and emotional impacts on siblings of individuals with IDDs. In fact, the linked lives concept makes the decision to caregive more complex and intense as various life events, experiences, and obligations affect the degree to which siblings become involved (or not) in caring for their brother/sister [9-11]. Regardless of the decision to involve/not involve, sibling relationships in families with children with IDDs are

different from those that exist between typically developing individuals [12] and are therefore worthy of attention.

1.1 Definitions of Constructs

In this study, we aimed to explore the associations between SSPs caregiving demands, their appraisals of those experiences, and the extent to which these are associated with empowerment and depressive symptoms. The inclusion of empowerment (protective factor) and depression (negative experience) reflects our attempt to balance our understanding and integration of depression does not necessarily imply pathology. Since depressive symptoms are more common among caregivers [13], the variable is of interest in particular because of public health implications.

Perceived social support is the subjective assessment of the adequacy of social support (mainly emotional and informational) from family, friends and significant others [14]. *Demands* refer to the cumulative “press” and juggling associated with (in this instance) providing care, including the cumulative impact of the functional limitations of the individual with IDD, weekly duration of caregiving, and responsibilities associated with employment. *Appraisals of caregiving* are individual, subjective assessments of caregiving. These assessments are based on caregiving challenges encountered and utilization of available coping resources [15]. *Empowerment* is the perception of caregiving efficacy in dealing with the situation, i.e., confidence in the ability to successfully navigate hurdles, perceptions of being in control, and the ability to rise above challenges [16] and includes not just surviving, but adapting and even thriving. *Depression* is an aspect of mood and is defined as feelings of hopelessness, guilt, worthlessness, and irritability accompanied by loss of interest in activities, fatigue, difficulty concentrating, etc. Individuals can experience depressive symptoms from mild and transient (associated with specific stressors) to significant and sustained difficulties [17].

1.2 Conceptual Model

To explore the associations between the various constructs; in this paper, we employ a conceptual model (See Figure 1) and our conceptual model is based on the Caregiver Empowerment Model (CEM). Jones et al. [18] proposed CEM to predict positive outcomes of caregiving among caregivers of the elderly. Similar to CEM, our goals were to explain and predict positive outcomes of caregiving; the conceptual model is an adaptation of CEM.

The conceptual model proposes that perceived social support and demands directly predict depression, appraisal of caregiving, and empowerment. Demands are predicted by the employment status of SSPs, the weekly duration of caregiving, and the functional level of the individual with IDD which further predict the appraisal of caregiving and depression. Finally, the appraisal of caregiving predicts depression and empowerment among SSPs.

Research on the presence of negative psychological functioning and behavioral issues, demand, social support, and appraisal of caregiving among siblings of individuals with IDD suggest inconsistent findings and warrant a more nuanced analysis of demographic and contextual variables. For example, O'Neill et al. [19] and Verte et al. [20] reported higher levels of anxiety and depression and behavioral problems among siblings of individuals with IDD, especially autism spectrum disorder. Similarly, Vermaes et al. [21] reported that siblings of individuals with chronic

health problems have higher rates of internalizing and externalizing problems. On the contrary, Rodgers et al. [22] do not support the above-stated findings among siblings of individuals with high-functioning Autism Spectrum disorder or Down syndrome [23] suggesting specific disabilities and their severity to be essential variables of interest.

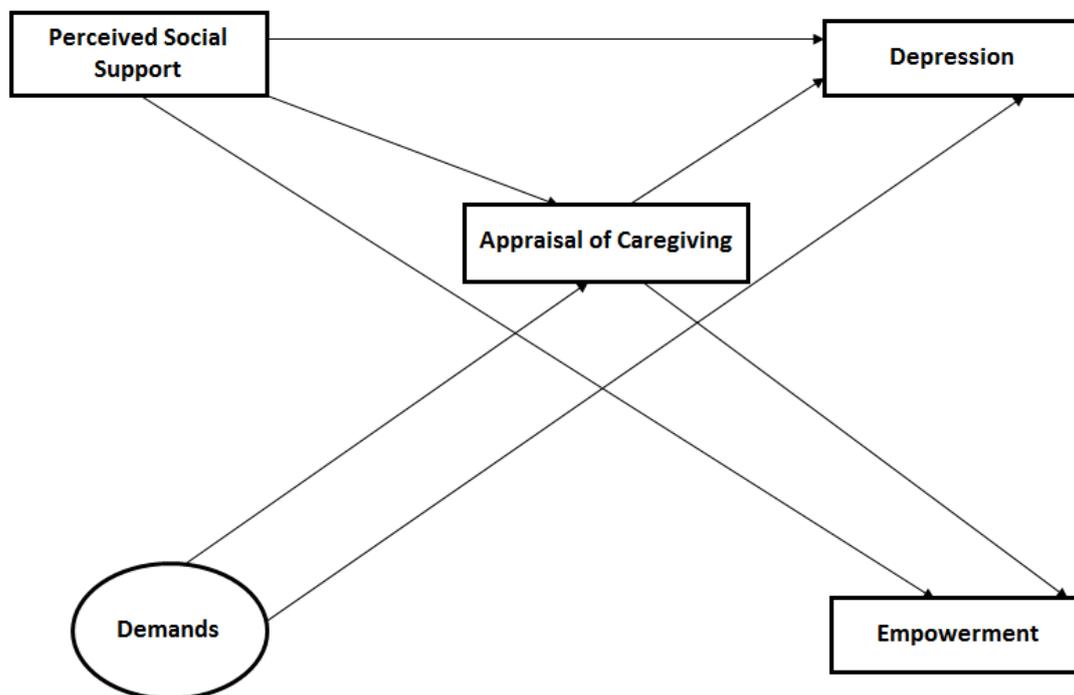


Figure 1 Conceptual model.

In addition to heightened anxiety, depression, and behavioral problems among siblings; specific disabilities and their severity can influence the relationship between siblings and individuals with IDD and perceptions of demand and appraisal. A positive sibling relationship can lead to higher levels of support and life satisfaction and lower levels of depressive symptoms and stress [24].

1.3 Perceived Social Support, Appraisal of Caregiving, and Depression

SSPs of individuals with IDD report a sense of obligation, consistent involvement, and an embrace of caregiving responsibilities at a young age [25]. During adulthood, these demands can result in stress, as sibling caregiving commitments are added to the normative stresses associated with work and family [26, 27]. The lack of adequate social and community support and programs [25] further exacerbates the stress, resulting in higher levels of depression [28] and negative appraisals of caregiving [29, 30].

Perceived lower social support among family caregivers of individuals with mental illnesses is associated with a significantly higher burden than that of better-supported counterparts [31] and perceived social support is shown to be the strongest predictor of appraisal of caregiving among family caregivers of traumatic brain injury [32]. In sum, although caregivers experience stress, dissatisfaction, and feelings of burden, their appraisals and adaptation are shaped by perceived social support [33]. We could locate no studies addressing perceived social support, appraisal of caregiving, and mental health of SSPs of individuals with IDD; however, they are germane to the experience of support provision and empirical exploration.

1.4 Demands, Appraisal of Caregiving, and Depression

For SSPs, demands and corresponding appraisals shift across the lifespan; as siblings age, the caregiving role requires modification, reevaluation, and accommodation [34]. Whereas the impact of employment duration, hours of caregiving, and the sibling's functional limitations on an appraisal of caregiving and depressive symptoms have not been studied among SSPs, there is literature on parents of children with IDD which we briefly review in the paragraphs below.

In general, individuals who provide care for more than 20 hours/week report higher negative appraisals of caregiving in terms of dissatisfaction, feelings of isolation, and burden [35]. In addition, employment can be affected by caregiving demands. Wong et al. [36] concluded that work-to-family spillover and inflexible work schedule were more detrimental to the health of parents of children with mental illnesses than to parents of typically developing children.

Interestingly, employment provides mental health benefits to the mothers of children, but these benefits disappear at high duration of employment (50 or more hours per week) [37]. However, highly stressed parents experience larger respite benefits from working outside the home [38]. It appears that the association between demands and outcome is not straightforward, and needs to be considered in light of other variables. Our conceptual model examines the extent to which SSPs experience work and caregiving as demands and whether these relate to appraisals of caregiving and individual functioning (depressive symptoms).

1.5 Perceived Social Support, Appraisal of Caregiving, and Empowerment

Kyzar et al. [39] completed a meta-analysis to examine the relationship between family support and family outcomes in families of children with moderate to severe IDDs. The researchers found that social support had a positive effect on family outcomes such as an improved sense of satisfaction and family functioning. Similarly, positive appraisal of caregiving is associated with higher caregiving efficacy and empowerment among spouses of individuals with dementia [40]. Park [41] suggested that approaching any stressful event as a challenge and learning opportunity can lead to personal growth. Perhaps that is why positive appraisal of caregiving may encourage a sense of efficacy and empowerment, and negative appraisals can result in a perceived loss of control.

1.6 Aims of the Current Study

In spite of a clear need for research on SSPs to inform policy and practice, little is known about the processes and outcomes of sibling care provision among the population of adult individuals with IDDs. As such, the main aims of the current study were to: (1) enable a descriptive understanding of SSPs and their brothers/sisters with IDDs, and (2) test a conceptual model of caregiving processes and outcomes, with a specified set of hypotheses. The caregiving model in Figure 1 depicts a set of hypothesized relations, e.g., that perceived social support and demand predict mood (depressive symptoms) directly as well as indirectly through mediation by an appraisal of caregiving. In addition, perceived social support predicts empowerment directly and indirectly after mediation by an appraisal of caregiving. The arrows in the model correspond to specific hypotheses articulated below. Based on the conceptual model and the gaps in the literature, we posed one descriptive and three model-related research questions (RQs), with

associated hypotheses:

RQ1 (descriptive): What are the characteristics of SSPs (in terms of age, gender, ethnicity, education, marital status, residential proximity, income, and employment level) and the individuals with IDD (in terms of their age, gender, functional limitations) whom they support?

RQ2: Are levels of perceived social support associated with depressive symptoms among SSPs and is this association predicted by appraisals of caregiving? We hypothesized that high perceived social support would be associated with low depressive symptoms and these associations also will be partially mediated by appraisals of caregiving.

RQ3: Are levels of perceived social support associated with a sense of empowerment among SSPs and is this association predicted by appraisals of caregiving?

We hypothesized that high perceived social support would be associated with higher levels of positive appraisals of caregiving and a higher sense of empowerment and these associations also will be partially mediated by appraisals of caregiving.

RQ4: Are demands and appraisal of caregiving associated with depressive symptoms among SSPs and is this association predicted by appraisals of caregiving?

We hypothesized that higher demands would be associated with higher depression scores and higher negative appraisal of caregiving and these associations also will be partially mediated by appraisals of caregiving.

2. Method

2.1 Data Collection and Participants

The data for this study were collected through a nationwide, web-based survey. SSPs were recruited through 245 formal and informal, local and state agencies and organizations, including The Sibling Leadership Network, The Sibling Network Project, The ARC, and the Association of University Centers on Disabilities. Study participants were self-identified siblings of individuals with IDD, 18 years or older, who provide some level of support to their brothers/sisters (see Table 1). The disabilities of the brother/sister were intellectual in nature and could co-occur with other developmental disabilities. All participants were English speakers and U.S. residents. Screening and filtering questions at the start of the survey and the inclusion of items that require reverse coding ensured the validity of the responses. The survey was open for six months.

The study was approved by the institutional review board at the authors' home institution before recruitment began. Survey responses were sent over a secure, SSL encrypted connection to maintain the anonymity of the participant and no identifiers (including IP addresses) were collected. Informed consent was obtained from all individual participants included in this study and random draws of four \$50 gift cards were provided as an incentive to complete the survey.

Table 1 Characteristics of Respondents (SSPs who Provide Care to their Brothers/Sisters with IDD) (N = 322).

Demographics	Valid Percent
Age (in years)	
18-25	35.7
26-53	29.8
36-45	9.9
46-55	14.3
55 and above	10.2
Gender	
Male	14.3
Female	85.4
Other	0.3
Ethnicity	
White	83
African American	4.2
Hispanic/Latino	5.6
Asian/Pacific Islander	4.9
Others	1.3
Education level	
Some high school	0.6
High school graduate or GED	9.1
Some college or 2-year degree	22.3
4-year college graduate	23.6
More than 4-year college degree	44.8
Average household income	
\$0-\$24,999	15.9
\$25,000-\$49,999	23.8
\$50,000-\$74,999	24.2
\$75,000-\$99,999	13.6
\$100,000-\$124,999	3.3
\$125,000-\$149,999	10.3
\$150,000-\$174,999	3
\$175,000-\$199,999	3.3
\$200,000 and up	1.7
Employment Status (duration in hours)	
Not employed	4.3
Yes, 1-10 hours/week	15.3
Yes, 11- 20 hours/week	5.5
Yes, more than 30 hours/ week	8.5
Others (student/seasonal)	51.1
Marital Status	
Never Married	14.0
Dating and/or cohabiting	31
Married	22.9
	36.9

Separated	0.7
Divorced	6.2
Remarried	2.3
Residential proximity from the B/S with IDD	
Lives with participant	32.3
1- 10 miles	21.7
11- 49 miles	16.5
50-149 miles	7.5
150- 249 miles	4.3
Beyond 250 miles	17.7
Caregiving Duration	
11- 20 hours/week	53.3
21-30 hours/week	29.5
31-40 hours/week	11.1
41-50 hours/week	2.3

2.2 Measures

2.2.1 Perceived Social Support

This was examined with the Multidimensional Scale of Perceived Social Support [14], a 12-item, 7-point scale which taps subjective assessment of emotional and informational support and the perceived adequacy of support from three sources: family, friends, and significant others. The responses range from very strongly disagree (1) to very strongly agree (7) with total scores ranging from 12 and 84; higher scores indicate higher perceived social support. Cronbach's coefficient alpha (α) value for the total scale was 0.84 in previous research [42] and 0.93 in the current sample. A sample item from the scale is "I can talk about my problems with my family."

2.2.2 Demands

Initially, we examined "demands" as a latent variable with three indicators: (1) functional abilities of the individual with IDD, (2) average weekly duration of caregiving in hours provided by SSPs, and (3) Weekly employment duration of SSPs in hours. The functional abilities and duration of caregiving measures, 11-item scales, were specifically created for the study but were adaptations of the functional abilities scale developed by Hodapp and Urbano [43] as part of their Adult Sibling questionnaire. The former assessed the level of independence/dependence of individuals with IDD on the activities of daily living on a five-point rating scale with responses ranging from 1 (completely dependent) to 5 (completely independent), and the latter explored the weekly hours of caregiving spent assisting with these activities of daily living. A sample item on functional abilities of the individual with IDD includes "On a scale of 1-5, with 1 being completely dependent to 5 being completely independent, "To what extent does your brother/sister with IDD perform day-to-day routine tasks such as preparing meals? A sample item on SSPs average weekly duration of caregiving in hours is, "On average, how much time per week do you spend performing tasks such as preparing meals for your brother/sister with IDD?"

On both scales, the total scores range between 11 and 55 with lower scores reflective of lower functional abilities/higher caregiving duration of the individual with IDD and higher demands on

SSPs. The third measure, weekly employment duration, sought information on the number of hours for which participants were employed. The variable is a categorical item with 5 options and responses ranging from 0 to more than 30 hours/week. The possible range of total scores was between 1 and 5, with lower scores indicating lower demands on SSPs.

However, as indicated below, the initial measurement model produced a poor fit (significant chi-square). On further investigation, we concluded that a high Cronbach's alpha ($\alpha = 0.94$) for the functional level of individuals with IDD and weekly caregiving duration indicated these might be acting as one scale rather than two different scales. Hence, the scores of the functional level and weekly caregiving duration were combined to form one new exogenous variable "demand," and employment duration was used as a second exogenous variable.

2.2.3 Appraisal of Caregiving

The construct was assessed using the Appraisal of Caregiving Scale-Revised [44], which measures subjective perceptions of caregiving stressors and the perceived ability to cope with the situation. It is a 27-item, 5-point Likert scale with total scores ranging from 27 to 135. Higher scores signify more positive appraisals of caregiving. Cronbach's α was 0.86 in previous research [44] and 0.91 in the current study. A sample item from the scale is "My brother or sister is too demanding."

2.2.4 Depressive Symptoms

Symptoms were self-reported via the Center for Epidemiologic Studies Depression Scale (CES-D), a measure of depressive symptoms experienced in the past week [45, 46]. The scale includes 20 items on a 4-point scale; total scores range from 0 to 60 and higher item and total scores indicate more depressive symptoms. Cronbach's α in prior research was 0.85 [45] and 0.92 in the current sample.

2.2.5 Empowerment

Empowerment was measured through the Caregiver Empowerment Scale [16], a 5-point Likert scale consisting of 30 items. Total scores range from 30 to 150, with higher scores indicating higher caregiver self-confidence and belief that s/he not only has the capacity to respond to support demands but also thrive in the situation and rise above the challenge. In the current sample, α was .95. An item from the scale is "I know how to influence the political system to advance service and research agenda for individuals with intellectual disabilities." Additionally, the errors of depression and empowerment were correlated as it may be possible that depressive symptoms among SSPs might be influencing their empowerment and vice versa.

2.2.6 Data Analysis

We employed structural equation modeling (SEM) to test the proposed conceptual model using SPSS AMOS 22.0 software to examine whether the data fit the hypothesized model. (As suggested earlier, the measurement model did not hold.) Data were screened for missing values and to ascertain patterns in missingness. Since AMOS uses full information maximum likelihood (FIML) estimation, it was used to estimate missing data as FIML has been shown to outperform most

common methods of handling missing data, including listwise and pairwise data deletion, and mean substitution [47]. Missing data ranged between 4.7% - 19% across items. We examined model fit with chi-square (χ^2), the comparative fit index (CFI), and the root mean square of error approximation (RMSEA). We selected these measures because a) CFI performs well even when the sample size is small [48], b) RMSEA is sensitive to the number of parameter estimates, as it favors the best fit and rewards parsimony [49] and c) these are most commonly used measures [49]. A non-significant χ^2 , a value of CFI \geq 0.95, and RMSEA below 0.05 indicate good fit [50].

3. Results

3.1 Descriptive Findings

Tables 1, 2, 3, and 4 depict the characteristics of 322 SSPs whose responses were included in the analyses and the reported characteristics of their brothers/sisters with IDD. Among the remainder ($n = 39$), data were completely missing, participants were less than 18 years old, or SSPs were former (not current) caregivers. Most (35.7%) SSPs were 18-25 years old. A majority were female (85.4%) and White (83%). Respondents resided all across the U.S., and over half (54%) reported co-residing or living within 10 miles of their siblings. The mean age of siblings with IDDs was 32 ($SD = 14.2$), and they were 63.3% male. Nearly all (94.1%) participants indicated that their sibling had co-occurring conditions. The average reported caregiving duration was 17.8 hours/week ($SD = 8.7$). Although a detailed analysis of Table 3 and Table 4 is beyond the scope of the paper but is being provided as further evidence for discussion and implications and limitations and next step sections.

Table 2 Characteristics of individuals with IDDs who received care from their adult siblings as reported by adult siblings. (N = 322).

Demographics	Valid Percent
Gender	
Male	63.3
Female	34.7
Additional/Co-occurring disabilities	
No other condition	5.9
Sensory impairment	18.3
Language and communication disorders	38.5
Physical motor	27.3
Behavioral	32.3
Learning	42.5
Emotional problems	17.7
Mental illnesses	17.4
Other conditions	28.3
Daily Activities	
Works in a paid job within the community independently	5.0
Works in a paid job with assistance	13.3
In school or training for future job	36.5

Volunteer activities	10.3
Does not work	16.6
Other	18.3
Weekly duration of employment/activities in hours/week	
40 hours or more	11.7
20-39 hours	46.2
1-19 hours	27.1
Does not work	15.1
Level of complete independence on selected tasks	
Walk	63.6
Speak	44.0
Read	21.0
Take medications	4.8
Medical appointments	3.8
Preparing meals	5.2
Grooming and personal hygiene	8.9
Household tasks	5.8
Financial tasks	2.4
Public transport	7.4
Others (living alone at night, assistance with eating, etc.)	100.0

Table 3 Means and standard deviations of model variables.

	<i>N</i>	<i>M</i>	<i>SD</i>
1. Social Support	253	64.3	15.9
2. Appraisal of Caregiving	225	60.2	16.9
3. Depression	241	20.4	10.8
4. Empowerment	216	107	21.5

Table 4 Pearson correlations between model variables.

	CD	DEP	FA	PSS	ACS	EMP
1. CD	-	.087	.351**	-.005	.071	.174*
2. DE		-	-.019	-.426**	.357**	-.492**
3. FA			-	-.060	-.064	.079
4. PSS				-	-.394**	.396**
5. ACS					-	-.536**
6. EM						-

* $P < 0.05$; ** $P < 0.01$

CD - Duration of Caregiving; DEP- Depression; FA- Functional Abilities; PSS- Perceived Social Support; ACS- Appraisal of Caregiving; EMP- Empowerment

3.2 Model-Related Findings

The model fit among perceived social support, demands, employment duration, appraisal of caregiving, depressive symptoms, and empowerment was tested and was found to be adequate ($\chi^2_{(6)} = 12.2, p = .057; RMSEA = .05; CFI = .968$). As depicted in Figure 2 (only significant paths are shown) significant positive associations were found between social support and empowerment ($\beta = .281, p < .001$). The positive associations indicate that SSPs with higher social support appraised caregiving more positively and felt more empowered. Social support was negatively associated with depression ($\beta = -.216, p < .001$), indicating that SSPs with higher social support experienced significantly fewer depressive symptoms. Demand and employment duration did not relate significantly to sibling appraisals of caregiving or depression. Perceived social support was positively associated with a positive appraisal of caregiving ($\beta = .410, p < .001$) indicating that SSPs with higher perceived social support reported positive appraisals of caregiving. Similarly, the appraisal of caregiving was found to be positively associated with the empowerment ($\beta = .574, p < .001$), indicating that SSPs with a more positive appraisal of caregiving felt more empowered and therefore felt more in control of the caregiving processes.

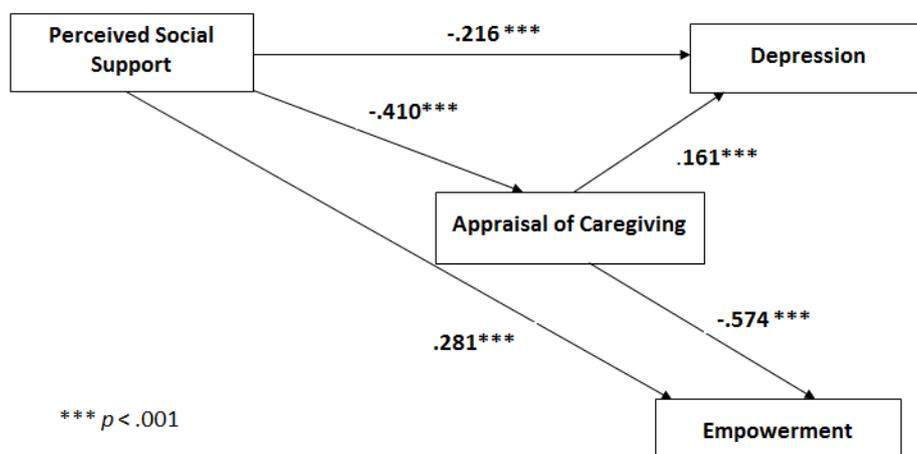


Figure 2 Final model (Includes significant pathways only).

On examining the indirect paths and because direct effects remained significant, appraisal of caregiving was noted to be a significant partial mediator between perceived social support and depression (*Sobel test statistic* = -3.26, $p < .001$) and between perceived social support and empowerment (*Sobel test statistic* = 4.721, $p < .001$).

4. Discussion and Implications

The results of this study reassert the idea of linked lives [8] and concur with findings of Altman and Blackwell [5], Fujiura et al. [51], and the Easter Seals survey [52] - the majority of SSPs in our sample lived with or near to their siblings. While the amount of care provision varied, it was equivalent to a part-time job ($M = 17.7$ hours per week, $SD = 8.7$). The commitment to reside close to one's brother/sister with IDD implies adult life interdependencies among adult sibling relationships, although, for some siblings, especially those who are younger, it can be circumstantial rather than an intentional choice.

The significant positive correlations between perceived social support and empowerment are unsurprising and are consistent with the recommendations of Kuhn et al. [53]. Chronic stress can result in feelings of loss of control over life events, and social support can help to reclaim that control by reducing feelings of isolation, providing opportunities for positive interactions, tangible help and respite, and providing broader focus on the stressor. Thus, SSPs may benefit from a network of individuals who can be part of their support group. In addition, future research may further help to identify the impact of levels/types of perceived social support on various aspects of empowerment.

The significant inverse relationship between perceived social support and depressive symptoms is similar to research in related areas [32, 33], suggesting that social support is correlated with positive appraisals of caregiving and positive mental health [30]. This study suggests that one's appraisal of the caregiving situation shapes sibling experiences in ways that can promote or detract from well-being. Because appraisal is essentially a cognitive proposition, it is open to intervention; as a consequence, this finding has important implications for the development of formal and informal interventions and support systems for caregivers [9, 27] As Park [41] suggests, approaching stressful events as a challenge and learning opportunity can lead to positive outcomes such as personal and psychological growth and a higher sense of empowerment. The association between negative appraisal of caregiving and empowerment in this study is consistent with Park's findings and underscores the notion that the meaning one makes of caregiving influences empowerment (and presumably efficacy).

The associations between social support, appraisal of caregiving, and depressive symptoms, and social support, appraisal of caregiving, and empowerment underscore the need to strengthen support programs and policies for the SSPs of individuals with IDD. Researchers have found that most SSPs feel unprepared and anxious about caregiving responsibilities [54] and need assistance with providing daily care [27]. Affiliation with support groups is associated with a positive appraisal of caregiving and lower depressive symptoms [39]. Therefore, formal support systems (e.g., residential programs, health care providers and more) should consider adopting universal approaches to partnering with and strengthening evidence based adaptive coping [21] among all family members especially siblings and become beneficiaries of Lifespan Respite Care Act, the Family Medical Leave Inclusion Act, the Community Choice Act, and caregiver tax credits [11].

In the absence of formal support systems, caregiving stress may extend beyond what is appraised as reasonable by SSPs, and negative outcomes may be more likely [9, 11].

5. Limitations and Next Steps

The current study has some limitations. First, as a cross-sectional study, the purpose of the study was to provide a snapshot of variables associated with depression and empowerment as potentially mediated by caregiving appraisals. Because the responses were collected through a survey that occurred at a single point in time, the sequence of events causality/directionality cannot be inferred. Second, the cross section is a relatively small, homogenous sample of SSPs, and their lack of diversity (age, race) echoes in a different vein the concern of Farrell et al. [1] over the "mismatch when demography is considered." Third, the online nature of the survey may have excluded subsets of the population that are not connected to the Internet [2]. Fourth, most of the SSPs were recruited through various local, state, and federal organizations. Therefore, the SSPs

who participated may have stronger social support systems compared to SSPs in general. Finally, even though the study enabled a framework to examine issues such as SSPs perceptions of social support, demands, appraisal of caregiving, depressive symptoms, and sense of empowerment, still there are many unanswered questions which may have implications for future research. Tables 3 and 4 suggest significant relationships between variables and therefore in-depth analysis of the following research questions is needed. For example, what are the age-based, SES, race-based, and type of caregiving based (physical, emotional, & financial) differential outcomes for SSPs? What are the positive aspects of caregiving and how do they influence the experience of SSPs? What are the social, economic, systemic, family, and individual factors that influence the adaptive coping of SSPs and their families? In the light of inadequate annual spending for family support of an individual with IDD, raising above questions are warranted.

We find model fit to be adequate; however, the fit can be substantially improved with theoretically sensible modifications such as the inclusion of covariance paths between perceived social support and empowerment, depression and empowerment, and perceived social support and depression instead of direct pathways.

We concur with the suggestions of other scholars [27] regarding the need to more closely examine the caregiving factors associated with well-being and encourage the development and provision of formal and informal supports to maintain these roles. The commitment of sibling care providers and the relative cost of inadequate support of their efforts may be sufficient justification for additional attention to research and practice. Further, the extent to which sibling efforts reduce publicly funded costs of care and enhance the quality of life among individuals with IDD provides a compelling rationale to invest further in understanding and supporting their resilience in the face of adversity.

Author Contributions

As first author, Mamta Saxena led the following: conceptualization of the study, research design, model specification, data collection and analysis, and interpretation of findings, as well as writing, revising, and editing the manuscript. Anne Farrell assisted with study conceptualization, research design, data collection and analysis, and interpretation, as well as the writing, revising, and editing the manuscript. Kari Adamsons assisted with the original conceptualization and model specification, running of analyses, and overall feedback and revisions to the manuscript.

Competing Interests

The authors have declared that no competing interests exist.

References

1. Farrell AF, Krahn GL. Family life goes on: Disability in contemporary families. *Fam Relat.* 2014; 63: 1-6.
2. American community survey, 2017. Retrieved from https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_11_1YR_S1810&prodType=table.

3. Lulinski A, Jorwic NT, Braddock D. Rebalancing of long-term supports and services for individuals with intellectual and developmental disabilities in the united states. Data Brief (2). Boulder: States of the States in Intellectual and Developmental Disabilities Project, Coleman Institute for Cognitive Disabilities, University of Colorado. 2018.
4. Hodapp RM, Sanderson KA, Meskis SA, Casale EG. Adult siblings of persons with intellectual disabilities: Past, present, and future. *Int Rev Res Deve Disabil*. 2017; 53: 163-202.
5. Altman BM, Blackwell DL. Disability in us households, 2000-2010: Findings from the national health interview survey. *Fam Relat*. 2014; 63: 20-38.
6. Swenson S, Lakin C. A wicked problem: Can governments be fair to families living with disabilities? *Fam Relat*. 2014; 63: 185-191.
7. Sra SK. Emotional adjustment of parents and siblings of individuals with severe psychopathology. *J Math Psychol*. 2013; 0; 1-23.
8. Elder Jr GH, Kirkpatrick Johnson M. The life course and aging: Challenges, lessons and new directions. *Invitation to the life course: Toward new understandings of later life*. Amityville. New York: Baywood Publishing Company, Inc; 2003: 49-89.
9. Burke MM, Fish T, Lawton K. A comparative analysis of adult siblings' perceptions toward caregiving. *Int Dev Disabil*. 2015; 53: 143-157.
10. Rossetti Z, Hall S. Adult sibling relationships with brothers and sisters with severe disabilities. *Res Practi Persons Severe Disabil*. 2015; 40: 120-137.
11. Saxena M. Variables that can enhance and complicate sibling caregiving of individuals with intellectual and developmental disabilities. *J Policy Pract Inte Disabil*. 2015; 12: 210-219.
12. Orsmond GI, Kuo HY, Seltzer MM. Siblings of individuals with an autism spectrum disorder: Sibling relationships and wellbeing in adolescence and adulthood. *Autism*. 2009; 13: 59-80.
13. Family caregiving alliance, 2018. Retrieved from <https://www.caregiver.org/depression-and-caregiving>.
14. Zimet GD, Dahlem NW, Zimet SG, Farley GK. The multidimensional scale of perceived social support. *J Personality Assess*. 1988; 52: 30-41.
15. Lawton MP, Morton H. Kleban, Miriam Moss, Michael Rovine, Allen Glicksman. Measuring caregiving appraisal. *J Gerontol*. 1989; 44: 61-71.
16. Degeneffe CE, Chan F, Dunlap L, Man D, Sung C. Development and validation of the caregiver empowerment scale: A resource for working with family caregivers of persons with traumatic brain injury. *Rehabil Psychol*. 2011; 56: 243-250.
17. Centers for disease control & prevention, 2015. Retrieved from <http://www.cdc.gov/Features/Depression>.
18. Jones PS, Winslow BW, Lee JW, Burns M, Zhang XE. Development of a caregiver empowerment model to promote positive outcomes. *J Fam Nurs*. 2011; 17: 11-28.
19. O'Neill LP, Murray LE. Anxiety and depression symptomatology in adult siblings of individuals with different developmental disability diagnoses. *Res Dev Disabil*. 2016; 51-52: 116-125.
20. Verte S, Roeyers H, Buysse A. Behavioural problems, social competence and self-concept in siblings of children with autism. *Child: Ca Health Dev*. 2003; 29: 193-205.
21. Vermaes IP, van Susante AM, van Bakel HJ. Psychological functioning of siblings in families of children with chronic health conditions: A meta-analysis. *J Pediat Psychol*. 2012; 37: 166-184.

22. Rodgers JD, Warhol A, Fox JD, McDonald CA, Thomeer ML, Lopata C, et al. Minimal risk of internalizing problems in typically-developing siblings of children with high-functioning autism spectrum disorder. *J Child Fam Stud*. 2016; 25: 2554-2561.
23. Laura K, Deborah D. Psychosocial adjustment in siblings of children with autism. *J Child Psychol Psychiat*. 2010; 43: 225-232.
24. Tomeny TS, Ellis BM, Rankin JA, Barry TD. Sibling relationship quality and psychosocial outcomes among adult siblings of individuals with autism spectrum disorder and individuals with intellectual disability without autism. *Res Dev Disabil*. 2017; 62: 104-114.
25. Rosemary T, Karl A, Aniela W. Continuity, commitment and context: Adult siblings of people with autism plus learning disability. *Health Soc Ca Commun*. 2013; 21: 480-488.
26. Burke MM, Lee CE, Arnold CK, Owen A. The perceptions of professionals toward siblings of individuals with intellectual and developmental disabilities. *Intell Dev Disabil*. 2017; 55: 72.
27. Arnold CK, Heller T. Caregiving experiences and outcomes: Wellness of adult siblings of people with intellectual disabilities. *Curr Dev Dis Rep*. 2018; 5: 143-149.
28. Jacobs L. Psychological adjustment and social support in siblings of individuals with disabilities. *Dissertations & Theses - Gradworks*. 2015.
29. Heejung K, Mido C, Karen R, Sunha K. Predictors of caregiver burden in caregivers of individuals with dementia. *J Adv Nurs*. 2012; 68: 846-855.
30. Umberson D, Montez JK. Social relationships and health a flashpoint for health policy. *J Health Soc Behav*. 2011; 51: 54-56.
31. Hsiao CY. Family demands, social support and caregiver burden in taiwanese family caregivers living with mental illness: The role of family caregiver gender. *J Clin Nurs*. 2010; 19: 3494-3503.
32. Hanks RA, Rapport LJ, Stephen V. Caregiving appraisal after traumatic brain injury: The effects of functional status, coping style, social support and family functioning. *Neurorehabil*. 2007; 22: 43-52.
33. Dilek DSL, Ozlem B. Predicting depressive symptoms among the mothers of children with leukaemia: A caregiver stress model perspective. *Psychol Health*. 2011; 26: 585-599.
34. Coyle CE, Kramer J, Mutchler JE. Aging together: Sibling carers of adults with intellectual and developmental disabilities. *J Policy Pract Intell Disabil*. 2014; 11: 302-312.
35. National alliance of caregiving, 2015. Caregiving in the US. Retrieved from https://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf.
36. Wong JD, Mailick MR, Greenberg JS, Hong J, Coe CL. Daily work stress and awakening cortisol in mothers of individuals with autism spectrum disorders or fragile x syndrome. *Fam Relat*. 2014; 63: 135-147.
37. Scharlach AE. Caregiving and employment: Competing or complementary roles? *Gerontologist*. 1994; 34: 378-385.
38. Morris LA. The impact of work on the mental health of parents of children with disabilities. *Fam Relat*. 2014; 63: 101-121.
39. Kyzar, K.B, Turnbull, A.P, Summers, J.A, et al. The relationship of family support to family outcomes: A synthesis of key findings from research on severe disability. *Res Pract Persons Severe Disabil*. 2012; 37: 31-44.

40. Bookwala J, Schulz R. The role of neuroticism and mastery in spouse caregivers' assessment of and response to a contextual stressor. *J Gerontol B Psychol Sci Soc Sci.* 1998; 53: P155-164.
41. Park CL. Stress-related growth and thriving through coping: The roles of personality and cognitive processes. *J Soc Issues.* 1998; 54: 267-277.
42. Zimet GD, Powell SS, Farley GK, Werkman S, Berkoff KA. Psychometric characteristics of the multidimensional scale of perceived social support. *J Pers Assess.* 1990; 55: 610-617.
43. Hodapp RM, Urbano RC. Adult siblings of individuals with down syndrome versus with autism: Findings from a large-scale us survey. *J Intellect Disabil Res.* 2010; 51: 1018-1029.
44. Lawton MP, Moss M, Hoffman C, Perkinson M. Two transitions in daughters' caregiving careers. *Gerontologist.* 2000; 40: 437-448.
45. Radloff LS. The ces-d scale: A self-report depression scale for research in the general population. *Applied Psychol Meas.* 1977; 1: 385-401.
46. Gomez R, McLaren S. The center for epidemiologic studies depression scale: Invariance across heterosexual men, heterosexual women, gay men, and lesbians. *Psychol Assess.* 2017; 29: 361-371.
47. Arbuckle JL, Marcoulides GA. Full information estimation in the presence of incomplete data. *Adv Struct Equation model: Issues and techniques.* 1996; 243: 277.
48. Bentler PM. Fit indexes, lagrange multipliers, constraint changes and incomplete data in structural models. *Multivariate Behav Res.* 2010; 25: 163-172.
49. Hooper D, Coughlan J, Mullen M. Structural equation modelling: Guidelines for determining model fit. *The Electronic J Bus Res Meth.* 2008; 6: 53-60.
50. Kenny DA. Measuring model fit. 2012. Retrieved from <http://davidakenny.net/cm/fit.htm>.
51. Fujiura GT. The political arithmetic of disability and the american family: A demographic perspective. *Fam Relat.* 2014; 63: 7-19.
52. Seals E. Sibling disability study, 2013. Retrieved from <http://www.easterseals.com/explore-resources/siblings-study.html>.
53. Kuhn JC, Carter AS. Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *Am J Orthopsychiatry.* 2010; 76: 564-575.
54. Heller T, Kramer J. Involvement of adult siblings of persons with developmental disability. *Intell Dev Disabil.* 2009; 47: 208.



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