

Caregiving Roles of Siblings of Adults With Intellectual and Developmental Disabilities: A Systematic Review

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Abstract

As individuals with intellectual and developmental disabilities (I/DD) grow older, many siblings anticipate becoming caregivers for their brothers and sisters with I/DD. However, there is little extant research about the caregiving roles of siblings. The purpose of this review was to extend the literature by conducting a systematic literature review about sibling caregiving. To better understand this population, a systematic literature review was conducted about adult siblings of individuals with I/DD to examine the definition of caregiving, sibling caregiving experiences, and correlates of sibling caregiving. In total, 29 relevant studies were identified. Results indicate that **there is no consistent definition of sibling caregiving**. Further, **adult sibling caregivers reported caregiving benefits and challenges**. The literature is also mixed with respect to the correlates of sibling caregiving. It is necessary to conduct additional research to understand sibling caregiving for individuals with I/DD. Implications for future research, policy, and practice are discussed.

Keywords: adult siblings, caregiving, future planning, intellectual disabilities, sibling roles

Introduction

Individuals with intellectual and developmental disabilities (I/DD) are having increasingly longer lives. As life expectancy increases, adults with I/DD may experience age-related changes such as dementia, mobility challenges, or behavioral issues (Coyle, Kramer, & Mutchler, 2014). Therefore, **adults with I/DD may have greater needs for long-term services and supports** (Grossman, 2011). Unfortunately, there are limited disability services for adults with I/DD in the United States. In 43 out of 50 states, an estimated 357,241 individuals with I/DD are on waiting lists for long-term services and supports (Larson, Lakin, & Hill, 2013). **Formal service delivery systems often expect families to provide life-long supports** to individuals with I/DD (Swenson, 2005). Consequently, family members assume greater caregiving responsibilities for individuals with I/DD (Krauss, Seltzer, & Jacobson, 2005).

Recognizing that individuals with I/DD are beginning to outlive their parents, siblings (i.e., the offspring without disabilities) are often expected to be the caregivers for their brothers and sisters with I/DD (Burke, Taylor, Urbano, & Hodapp, 2012). Indeed, many parents report that they would like to shift their

caregiving responsibilities to their offspring without disabilities (Griffiths & Unger, 1994). Previous studies have indicated that many siblings may pursue caregiving (e.g., Heller & Arnold, 2010; Krauss, Seltzer, Gordon, & Friedman, 1996). Yet to date, we have little understanding of sibling caregiving even though a clearer understanding of caregiving is essential to support individuals with I/DD and their families (Bigby, 2008). Specifically, there is little understanding of the definition of sibling caregiving, the types of caregiving experiences among siblings, and the correlates of sibling caregiving. Therefore, the purpose of this review is to conduct a preliminary examination of sibling caregiving including its definition, types of experiences, and correlates.

Before exploring the perspectives of siblings toward caregiving, the definition of “caregiving” should be provided. Defining caregiving is crucial to ensure that researchers are using the same construct of caregiving. In 1987, Bulmer wrote a seminal article about caregiving. **Caregiving was defined as having three components: physical tending, material and psychological support, and concern about someone’s welfare.** However, in the disability literature, there is a lack of consensus about the definition of “caregiving” (Giovannetti & Wolff, 2010). Without a global definition of caregiving, it is difficult to identify the prevalence of caregivers of individuals with I/DD. Although the definition of caregiving from Bulmer (1987) was intended to broadly encompass caregiving, it is unknown whether Bulmer’s definition aligns with sibling caregiving. Thus, the definition of sibling caregiving should be explored.

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With respect to individuals with I/DD, parents have been the primary caregivers. The nature of caregiving includes both positive and negative effects. Indeed, many researchers have identified the negative effects of caregiving among parents; more recently, researchers have identified positive effects of caregiving (e.g., Rapanaro, Bartu, & Lee, 2007). While it is important to understand the nature of caregiving such that positive effects can be capitalized on and negative effects can be targeted for intervention, it is also necessary to consider the difference in caregiving experiences. Most research has focused on parent caregivers of individuals with I/DD even though siblings are increasingly expected to fulfill caregiving roles (Hodapp, Glidden, & Kaiser, 2005). In addition, sibling caregiving experiences may look different from parent caregiving experiences as siblings are likely to fulfill multiple caregiving roles for their brothers and sisters with I/DD, aging parents, and own offspring.

In a comprehensive review of the literature about siblings, Heller and Arnold (2010) identified 23 studies about siblings of individuals with I/DD. Specifically, they examined psychosocial outcomes of being a sibling, sibling relationships, and future planning. Heller and Arnold found that many siblings planned to become caregivers for their brothers and sisters with I/DD. However, caregiving responsibilities differed across studies. Such responsibilities ranged from being a legal guardian, providing financial support, or living with the brother/sister with I/DD. Further, there was very little research about correlates of sibling caregiving. To develop interventions for sibling caregivers, it is necessary to identify which siblings may become caregivers.

In a conceptual article, Saxena (2015) identified variables associated with sibling caregiving. Potential correlates reflected four domains: (1) individual characteristics of siblings, (2) characteristics of the brothers/sisters with I/DD and sibling relationship variables, (3) family-related factors, and (4) community resources and support. However, these potential correlates should be interpreted with caution as the article did not include a systematic literature review. In addition, Saxena's article included siblings of individuals with mental health diagnoses. However, there are significant differences between siblings of individuals with I/DD compared to mental health diagnoses (e.g., Greenberg, Seltzer, Orsmond, & Krauss, 1999). It is important to identify correlates for caregiving with respect to these groups separately.

The purpose of this review is to extend the literature by conducting a systematic literature review about sibling caregiving. The guiding questions for this review were: (1) How do studies define sibling caregiving? (2) What are the experiences of sibling caregivers of brothers and sisters with I/DD? and (3) Which variables correlate with sibling caregiving?

Method

Eligibility Criteria

The inclusionary criteria for this review were that each study: (1) was published in a peer-reviewed journal, (2) included empirical data, (3) included typically developing adult siblings of individuals with I/DD (e.g., autism spectrum disorder, intellectual disability, and Down syndrome) who were older than 18 years of

age, (4) was published between 1970 and 2016, (5) was published in English, and (6) focused on adult sibling caregiving roles. Given the Baby Boom generation and the longer lives of individuals with I/DD, there is a large population of individuals with I/DD outliving their parents creating the "club sandwich generation" among siblings of individuals with I/DD. To capture the effect of the Baby Boom generation and the increased need for caregiving among individuals with I/DD, the years of publication were limited from 1970 to 2016. Studies that only included siblings of individuals with mental health diagnoses were also excluded from the review as sibling relationships and caregiving differ in relation to whether a brother or sister has I/DD or a mental health diagnosis (e.g., Orsmond & Seltzer, 2007). In addition, opinion papers and literature reviews were excluded from this review.

Literature Search

Articles were identified in two phases. First, an online literature search was conducted through the University Library using the following databases: ERIC, PsychINFO, and Academic Search Complete. Multiple combinations of keywords and descriptions were used to define the participants (e.g., siblings, caregivers, brothers, sisters), the type of disability (e.g., autism, Down syndrome, intellectual disability, developmental disability, mental retardation), and the research topic (e.g., caregiving, future planning, transition). During the second phase, a hand search of reference lists from included studies and relevant book chapters was conducted.

The initial search yielded 3,488 studies. The titles of the articles were scanned. Articles that focused on children or adolescents were excluded; also, articles that were not relevant to our guiding questions (i.e., the definition of caregiving, caregiving experiences, and correlates of caregiving) were excluded. In total, 276 articles were selected for an abstract review; based on the abstracts, 204 articles were excluded that were irrelevant to our three guiding questions. The authors conducted a full article review of the remaining 72 articles. The authors then discussed which studies met the inclusionary criteria. The authors discussed any discrepancies until consensus was reached. The final number of studies meeting the inclusionary criteria was 29. See Table 1.

Coding Procedures

With 29 included studies, the authors coded the studies with respect to the study participants (e.g., sample size), research design (e.g., qualitative or quantitative), and findings. All included studies were independently coded by both authors. To assess reliability, the authors calculated the extent of agreement between the coders with respect to each code (e.g., sample size, method). Overall, there was 96.58% agreement between the coders. Specifically, with respect to the findings, both authors independently and distinctly coded the findings for each of the three guiding questions. Agreement was high for each question. For the codes that had disagreements, the authors discussed the codes until a consensus was reached.

TABLE 1
Summary of article review

Author(s)/year	Purpose of the study	Participants	Method	Main findings
Arnold, Heller, and Kramer (2012)	To identify the support needs of siblings of individuals with DD	N = 139 siblings	Survey	Siblings who plan to provide care for individuals with I/DD reported needing future planning and a formal support system.
Bigby et al. (2015)	To explore sibling roles and the relationships between siblings and group home staff	N = 31 siblings and group home staff (14 siblings)	Interview	Siblings played significant roles in the lives of their brothers/sisters with ID including: (1) monitoring formal care; (2) complementing formal care; (3) occupying formal roles; and (4) planning for the future. Sibling-staff relationships fluctuated over time.
Burke et al. (2015)	To examine the differences between current and future sibling caregivers	N = 42 siblings	Focus Group	Current (vs. future) sibling caregivers performed more formal responsibilities. Current sibling caregivers may better understand caregiving due to their experiences.
Burke et al. (2012)	To identify the correlates of future caregiving	N = 757 siblings	Survey	Future caregiving was expected when the parent had excellent health and the sibling; was female, was lone, had a closer sibling relationship, and lived closer to their brothers and sisters with I/DD.
Chadwick et al. (2013)	To gain insight into the support needs of family carers	N = 70 Family carers (5 siblings)	Focus Group	Sisters were concerned about future caregiving; they wanted service providers to listen to them and respect their wishes.
Chou et al. (2009)	To compare older and younger caregivers' well-being and plans	N = 787 family caregivers (97 siblings)	Survey	Siblings were likely to assume caregiving responsibilities for their brothers/sisters with ID when there was greater family income and greater family social support.
Chou et al. (2007)	To examine quality of life of caregivers of individuals with ID	N = 792 family carers (90 siblings)	Survey	Sibling caregivers (vs. mothers) were more likely to have a higher quality of life.
Cleveland and Miller (1977)	To determine the effect on siblings from having a brother or sister with ID	N = 162 siblings	Survey	There were a few negative effects of having a brother/sister with ID. Female (vs. male) siblings had more contact and closer sibling relationships. The oldest sister reported the most caregiving tasks.
Coyle et al. (2014)	To examine the process of transitioning caregiving from parents to siblings	N = 15 siblings	Interviews	Ongoing modifications of the caregiver role were required. Siblings who conducted future planning were more prepared for caregiving. Siblings reported the importance of formal and informal support.
Cuskelly (2016)	To examine adult siblings' intentions regarding caregiving and sibling relationships.	N = 36 siblings	Survey	Closer sibling relationships correlated with greater future caregiving. Siblings expected to assume caregiving when their parents were deceased. Some siblings were unprepared to discuss family caregiving.
Davys et al. (2010)	To examine future planning, parent wishes, and caregiving	N = 21 siblings	Survey	Siblings were concerned about their futures due to the impact of sibling caregiving. Siblings and parents were dissatisfied with services.
Davys et al. (2010)	To examine sibling perspectives toward future planning	N = 15 siblings	Interviews	Future planning varied across families; most plans lacked detail. Barriers to future planning were: parental anxiety, difficulty with service providers, and the lack of an open dialogue.

TABLE 1
Continued

Author(s)/year	Purpose of the study	Participants	Method	Main findings
Davys et al. (2010)	To explore the perceptions of siblings regarding future caregiving and to compare sibling and parent perceptions	N = 15 siblings	Interviews	Siblings reported varied roles: caregiver, advocate, mentor, financial supporter, and typical sibling. In regard to future planning, siblings reported conflicts among family members. Siblings were worried about insufficient and inappropriate services leading to more care demands.
Egan and Walsh (2001)	To examine the caregiving stress of sibling caregivers of individuals with ID	N = 39 siblings	Survey	Siblings who assumed caregiving roles were likely to be older than their brothers/sisters with ID and have less earned income. Siblings were more likely to have caregiving stress when there was less social support and their brothers/sisters with ID had less independence.
Greenberg et al. (1999)	To examine the correlates of sibling involvement	N = 119 siblings	Survey	Siblings provided less instrumental support when they had young children and lived further away from their brothers/sisters. Female (vs. male) siblings were more likely to provide emotional support.
Griffiths and Unger (1994)	To examine how parents and siblings perceive the demands of caregiving related to future planning	N = 41 dyads of parents and siblings	Survey	Siblings perceived that caregiving was stressful. When siblings were pessimistic about their brother/sister, they expressed less willingness to be involved with caregiving. Family communication about future planning increased the likelihood of future sibling caregiving.
Harland and Cuskelly (2000)	To understand concerns and current responsibilities of adult siblings of individuals with sensory disabilities	N = 6 siblings	Interviews	Sibling roles included providing respite, supporting communication, assisting with personal development, offering companionship, and being a sibling. Future concerns included: balancing roles, dealing with challenging behaviors, lack of future planning, and lack of support.
Heller and Caldwell (2006)	To examine the effectiveness of a future planning intervention	N = 48 caregivers (4 siblings)	Pre-post Survey	The future planning intervention significantly reduced caregiving burden and increased daily choice-making of individuals with DD.
Heller and Kramer (2009)	To identify the correlates of sibling involvement in future planning and caregiving	N = 139 siblings	Survey	Correlates included: age, higher degree of support reciprocity among siblings, having same-sex sibling dyads, closer geographical proximity between siblings, greater sibling contact, and having a positive view of the impact of the brother/sister with I/DD.
Holl and Morano (2014)	To understand the needs of future sibling caregivers	N = 15 siblings	Focus Group	Siblings were familiar with disability services and sibling support groups. Siblings reported that services were important.
Krauss et al. (1996)	To examine the sibling relationship and future roles of siblings of individuals with ID	N = 140 siblings	Survey	A few siblings planned to live with their brother/sister with ID. Greater sibling involvement was associated with: gender, maternal health, severity of the disability, and frequency of shared activities.
McGraw and Walker (2007)	To examine the sociocultural boundaries that sisters navigate	N = 10 sisters	Interviews	Siblings reported making sacrifices to care for their brothers/sisters; they also described caregiving rewards. Some siblings reported conflicts with their mothers about caregiving.

TABLE 1
Continued

Author(s)/year	Purpose of the study	Participants	Method	Main findings
Orsmond and Seltzer (2000)	To compare male and female siblings of adults with I/DD	N = 245 siblings	Survey	Female (vs. male) siblings were more involved with their brothers/sisters with I/DD. Male siblings reported greater concerns.
Rawson (2010)	To explore young adult siblings' perceptions of future planning and needed supports	N = 13 siblings	Interviews	Siblings anticipated future caregiving roles. Siblings reported struggling with balancing caregiving roles. Siblings reported concerns about the future and wanted to be involved in future planning.
Rimmerman and Raif (2001)	To compare the involvement of siblings of individuals with (vs. without) ID	N = 76 siblings	Survey	Siblings of individuals with (vs. without) ID were more likely to provide affective support to their brother/sister with I/DD.
Rossetti and Hall (2015)	To examine how siblings perceive their relationships with their brothers/sisters with I/DD	N = 79 siblings	Survey	Siblings felt frustrated and stressed with caregiving. Siblings were unprepared for the transition to caregiving. Siblings reported needing information and support to plan their transitions to caregiving roles.
Sonik et al. (2016)	To examine the sociodemographic and material hardship of sibling caregivers	N = 78 siblings	Survey	Sibling caregivers were more likely to be: female, Black, older, and less educated than other working-age heads of households.
Taggart et al. (2012)	To examine aging carer's caregiving demands and perceptions about support	N = 112 Caregivers (24 siblings)	Mixed methods	Siblings worried about future care options as their brothers and sisters were aging. Family caregivers reported that siblings should be involved in future planning.
Tozer and Atkin (2015)	To examine sibling relationships, advocacy, and future planning	N = 21 siblings	Interviews	Siblings struggled to balance caregiving roles and felt excluded from discussions about disability services.

ASD, autism spectrum disorder; DD, developmental disability; DS, Down syndrome; ID, intellectual disability; I/DD, intellectual and developmental disability; LD, learning disability.

Results

Participants

A total of 2,388 adult siblings of individuals with I/DD were included in the 29 studies. All participants were over 18 years old; ages ranged from 18 to 72. A few studies included siblings of individuals with I/DD and other participants (i.e., parents, group home staff), but only findings related to siblings of individuals with I/DD were reported in this review. The vast majority of participants were female. Specifically, 13 studies had samples wherein 80% of the participants were female. Of the studies which reported the race of the participants, most were White (91.34%, $n = 1,603$). Regarding the types of disabilities of the brothers and sisters with I/DD, intellectual disability (59.26%, $n = 1,456$) was the most common. Regarding geographic representation, 44.83% ($n = 13$) of the studies were conducted outside of the United States (e.g., Australia, Hong Kong).

Overview of the Results

The articles reviewed were categorized into three broad categories based on the guiding questions: the definition of caregiving ($n = 6$ articles), the experiences of sibling caregiving ($n = 15$ articles), and the correlates of sibling caregiving ($n = 13$ articles). Overall, the articles revealed: a lack of consensus about the definition of sibling caregiving; positive and negative sibling caregiving experiences; and mixed findings about the correlates of sibling caregiving. Below is a description of the findings in greater detail.

Definition of Caregiving

“Sibling caregiving” was defined differently across the studies. Most studies did not define caregiving. Only six studies included definitions of caregiving. Specifically, some studies defined caregiving as including three tasks: guardianship, residential arrangement, and companionship (Greenberg et al., 1999; Orsmond & Seltzer, 2000). In contrast, Burke et al. (2012, 2015) defined caregiving as providing support across five domains: securing residential arrangements, conducting financial arrangements, having legal guardianship, interacting with service delivery systems, and providing companionship for their brothers and sisters with I/DD. Co-residence with brothers and sisters with I/DD was another way to define sibling caregiving (Krauss et al., 1996). Comparatively, Sonik, Parish, and Rosenthal (2016) characterized sibling caregivers as individuals who self-reported as the “head of a household” of an adult with I/DD.

Caregiving Experience

Caregiving rewards. Only two studies specifically examined caregiving rewards. In the Burke, Fish, and Lawton (2015) study, focus groups were conducted with current and future sibling caregivers. Both current and future sibling caregivers reported enjoying close sibling relationships and bonding with their brothers and sisters with I/DD. In a study by McGraw and Walker

(2007), sibling participants reported experiencing personal growth as a result of caring for their brothers and sisters with I/DD.

Caregiving challenges. Fifteen studies identified caregiving challenges, which were grouped into four subcategories: caregiving demands, conflicts between mothers and siblings, effects from aging, and navigating the service delivery system.

Caregiving demands. Seven studies reported physical and/or emotional caregiving demands. For example, Taggart, Truesdale-Kennedy, Ryan, and McConkey (2012) found that almost 71% of current family caregivers, including parents and siblings, reported anxiety related to caregiving. In a study comparing parent and sibling caregivers of individuals with I/DD, sibling caregivers reported greater stress than parents (Chou, Lin, Chang, & Schallock, 2007). Also, caregiving stress seemed related to the characteristics of the brother/sister with I/DD. For example, when the brother or sister with I/DD had challenging behaviors (Burke et al., 2015; Harland & Cuskelly, 2000; Taggart et al., 2012) or fewer functional abilities (Egan & Walsh, 2001), siblings reported greater caregiving stress.

In addition to physical and emotional demands, sibling caregivers also reported struggles with finances and time management. For example, current sibling caregivers (vs. working-age adults) were more likely to live in poverty and require public assistance (e.g., Supplemental Security Income, Sonik et al., 2016). Further, siblings reported struggling to balance their caregiving roles and maintain their own livelihoods (Burke et al., 2015; Coyle et al., 2014; Davys, Mitchell, & Haigh, 2010, 2014; Harland & Cuskelly, 2000; McGraw & Walker, 2007; Rawson, 2010; Tozer & Atkin, 2015). Such struggles in balancing responsibilities led siblings to report feeling lonely (Burke et al., 2015). Despite these challenges, caregiving burden can be addressed by family-focused interventions. For example, Heller and Caldwell (2006) developed a future planning intervention including individuals with I/DD and their parents and siblings. Intervention (vs. control) group participants demonstrated significantly reduced caregiving burden (Heller & Caldwell, 2006).

Conflicts between parents and siblings. Four studies found that siblings struggled with conflicts with their mothers (Davys et al., 2010, 2014, 2016; McGraw & Walker, 2007). Specifically, siblings reported that their mothers had a “do it all” caregiving style and refused to let anyone else help provide caregiving. Further, siblings reported a lack of open communication between parents and siblings (Davys et al., 2010, 2014).

Effects from aging. Three studies found that sibling caregivers worried about aging effects (i.e., aging parents, aging individuals with I/DD, and aging siblings) (Coyle et al., 2014; Heller & Caldwell, 2006; Taggart et al., 2012). In a study by Coyle et al. (2014), 15 current sibling caregivers reported worrying about their aging parents and struggling with helping their brothers or sisters with I/DD understand their parents’ declining health. Siblings were also concerned about the impact of aging on their brothers and sisters with I/DD (e.g., the onset of dementia). Last, siblings faced their own aging and health-related issues; siblings worried about who would fulfill their caregiving roles (Heller & Caldwell, 2006).

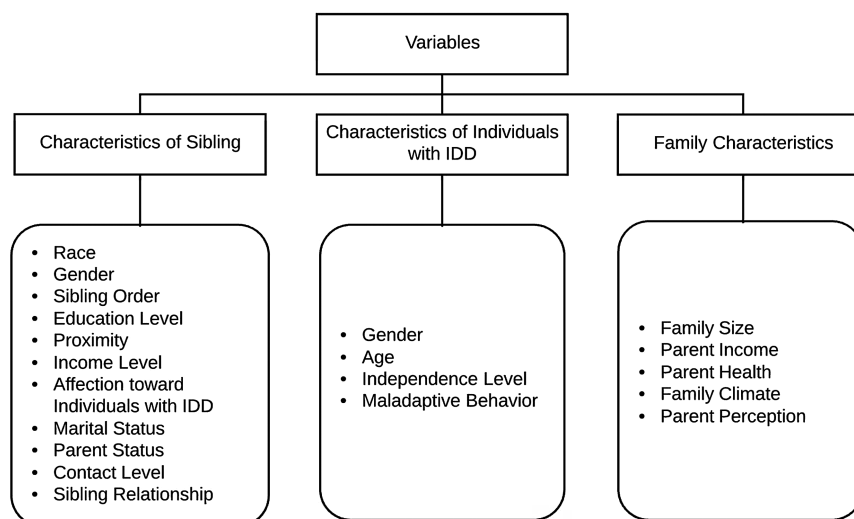


FIGURE 1

Variables related to sibling caregiving.

Navigating the service delivery system. Ten studies reported that it was difficult for sibling caregivers to navigate the service delivery system. Both future and current sibling caregivers reported that there is little information, support, and guidance to navigate services. For example, current sibling caregivers spent a lot of time and effort to acquire guardianship (Burke et al., 2015). Moreover, working with professionals in the disability service system was another struggle for both future and current sibling caregivers (Bigby, Webber, & Bowers, 2015; Heller & Caldwell, 2006; Tozer & Atkin, 2015). Current sibling caregivers reported struggling to build positive relationships with professionals. Sometimes, professionals did not involve siblings in decision making, which resulted in a lack of communication between professionals and siblings.

Correlates of Sibling Caregiving

Across 13 studies, researchers identified correlates of sibling caregiving. Correlates of sibling caregiving related to characteristics of the: siblings, individuals with I/DD, and families. See Figure 1.

Characteristics of siblings. Twelve studies identified sibling characteristics, which correlated with caregiving: race, gender, sibling order, education level, proximity, income, affection, marital status, parent status, contact level, and sibling relationship.

Race. Only one article discussed race as a correlate of sibling caregiving (Sonik et al., 2016). Notably, because most studies had primarily White participants, it would have been difficult to determine whether race was a correlate of caregiving. However, Sonik et al. (2016), using a national data set, found that, compared to the working age adult population, current sibling caregivers were more likely to be Black.

Gender. The research is mixed regarding the impact of gender on caregiving. In most studies ($n = 7$), female (vs. male) siblings were more likely to be caregivers (Cleveland & Miller, 1977; Greenberg et al., 1999; Griffiths & Unger, 1994; Krauss et al., 1996; McGraw & Walker, 2007; Orsmond & Seltzer, 2000; Sonik et al., 2016). Orsmond and Seltzer (2000) found that females (vs. males) were more likely to currently complete caregiving tasks. Conversely, Cuskelly's (2016) found no correlation between gender and future sibling caregiving.

Sibling order. Cleveland and Miller (1977) found that siblings who were older (vs. younger) than their brothers/sisters with I/DD were more likely to anticipate future caregiving.

Education level. Sonik et al. (2016) reported that, compared to working age adults, current sibling caregivers were more likely to be less educated.

Proximity. Across four studies, siblings were more likely to become future caregivers when siblings lived closer (vs. farther) to their brothers or sisters with I/DD (Burke et al., 2012; Cuskelly, 2016; Greenberg et al., 1999; Heller & Kramer, 2009).

Income. Three studies examined the correlation between sibling income level and caregiving (Egan & Walsh, 2001; Krauss et al., 1996; Sonik et al., 2016). In a study by Sonik and colleagues (2016), compared to the working age adult population, current sibling caregivers were more likely to have lower income and receive public benefits. Similarly, compared to siblings who lived in their parent's home, current sibling caregivers were more likely to earn less income (Egan & Walsh, 2001). However, Krauss et al. (1996) reported no significant correlation.

Sibling affection toward their brothers and sisters with I/DD. Siblings who had positive affect toward the brothers and sisters with I/DD were more likely to anticipate future caregiving responsibilities (Griffiths & Unger, 1994; Heller & Kramer, 2009; Orsmond & Seltzer, 2000). Griffiths and Unger (1994) reported that siblings were less interested in providing future caregiving

when they negatively perceived the impact of having a brother or sister with I/DD.

Marital status. Across two studies, siblings who were single (vs. married) were more likely to be current sibling caregivers (Chou, Lee, Lin, Kroger, & Chang, 2009; Sonik et al., 2016). However, Burke et al. (2012) reported no relation between marital status and future sibling caregiving.

Parent status. Siblings were less likely anticipate providing instrumental and emotional caregiving support to their brothers and sisters with I/DD when they had their own children under 18 years of age at home (Burke et al., 2012; Greenberg et al., 1999).

Contact level. Two studies reported positive correlations between sibling contact and caregiving (Heller & Kramer, 2009; Krauss et al., 1996). Siblings with at least (vs. less than) weekly contact with their siblings were more likely to anticipate co-residing with brothers and sisters with I/DD compared to siblings who intended to live apart (Krauss et al., 1996).

Sibling relationship. Four studies found that close sibling relationships related to a greater likelihood of future caregiving (Burke et al., 2012; Cuskelly, 2016; Greenberg et al., 1999; Heller & Kramer, 2009).

Characteristics of Individuals with I/DD. Six studies reported correlations between the characteristics of persons with I/DD and caregiving. Characteristics of persons with I/DD included: gender, age, level of independence, and maladaptive behaviors.

Gender. Four studies examined the influence of the gender of the individual with I/DD in relation to sibling caregiving (Greenberg et al., 1999; Heller & Kramer, 2009; Krauss et al., 1996; Orsmond & Seltzer, 2000). The four studies found that when the sibling and brother and sister with I/DD were the same sex, siblings were more likely to anticipate future caregiving roles.

Age. Only one study examined the influence of the age of the brother or sister with I/DD in relation to sibling caregiving. Heller and Kramer (2009) found that siblings had greater future caregiving responsibilities if their brothers or sisters with I/DD were older (vs. younger).

The level of independence of brother or sister with the I/DD. In two studies, future sibling caregivers were more likely to anticipate caregiving when their brothers/sisters with I/DD had higher levels of independence (Krauss et al., 1996; Rimmerman & Raif, 2001) while Seltzer et al. (1991) reported opposite findings. However, other studies found no relation between independence and caregiving (Heller & Kramer, 2009).

Maladaptive behaviors of person with the I/DD. Regarding problem behaviors, the research is mixed. Three studies have found that maladaptive behaviors were not related to future sibling caregiving (Burke et al., 2012; Greenberg et al., 1999; Heller & Kramer, 2009). However, Cuskelly (2016) reported that when the brother or sister with I/DD had more maladaptive behaviors, siblings reported poorer sibling relationships, which may relate to less caregiving.

Family characteristics. Eight studies examined the correlation between family characteristics and sibling caregiving. Family characteristics included family size, parent income level, parent

health, family climate, and parent perceptions toward sibling caregiving.

Family size. Compared to multiple siblings, lone siblings (i.e., the only child without I/DD in a family) were more likely to anticipate future caregiving roles (Burke et al., 2012).

Parent income level. When income was higher (vs. lower), parents were more likely to transition their caregiving roles to their offspring without disabilities (Chou et al., 2009).

Parent health. Sibling caregiving could also be influenced by parent health (Burke et al., 2012; Cuskelly, 2016; Krauss et al., 1996; Orsmond & Seltzer, 2000). Burke et al. (2012) found that when parents were in poor health, siblings were less likely to anticipate future caregiving responsibilities. However, other research has found a negative correlation regarding parent health and future sibling caregiving (Cuskelly, 2016; Krauss et al., 1996; Orsmond & Seltzer, 2000).

Family climate. Five studies examined family climate as a correlate. In general, family climate was defined as the interpersonal relationships among family members. For example, close (vs. distant) mother-child relationships were associated with a greater likelihood of future sibling caregiving (Greenberg et al., 1999; Krauss et al., 1996; Rimmerman & Raif, 2001). In a study by Griffiths and Unger (1994), siblings were more likely to anticipate future caregiving roles when there was family communication about future planning.

Parent perceptions toward sibling caregiving. When parents had more positive perceptions toward sibling involvement, siblings were more likely to anticipate future caregiving roles (Griffiths & Unger, 1994).

Discussion

To understand sibling caregiving roles, a systematic literature review was conducted. There were four main findings. First, across the studies, the definition of caregiving varied. Lack of agreement about the definition of caregiving is problematic as it is necessary to have an operational definition of a construct before one can effectively understand it. It seemed that Burke et al. (2012) had the most complete definition of caregiving which included five domains: securing residential arrangements, assisting with financial arrangements, having legal guardianship, interacting with the service delivery system, and providing companionship. In addition to describing the domains of caregiving, the definition of caregiving may also include other facets (e.g., the number of hours spent caregiving). Moving forward, it is necessary to define sibling caregiving.

Second, siblings reported benefits and challenges to caregiving. Three studies discussed caregiving benefits including watching the growth of individuals with I/DD, having close sibling relationships, providing parents with respite, and enjoying their own personal growth. However, more research is needed about caregiving benefits. As Heller and Kramer (2009) mentioned, understanding positive aspects of caregiving could result in a greater willingness for siblings to fulfill caregiving roles. In recent years, there has been a shift in the research from focusing on negative outcomes to the positive benefits of having a family

member with I/DD (Dykens, 2005). There is a growing need for examining rewards of sibling caregiving.

In addition to caregiving benefits, several studies reported different caregiving challenges: experiencing physical, economic, and emotional demands, addressing aging family members, and navigating the disability service delivery system. These caregiving challenges posit the need for interventions for sibling caregivers. Such interventions should attempt to ameliorate some of these challenges. For example, one of the reported caregiving challenges was lack of information about the disability service delivery system. To address this, trainings about adult services could be offered to siblings.

Third, there are many correlates of sibling caregiving. Among these correlates, researchers have agreed on a few characteristics such as proximity between siblings, sibling affect toward the brother/sister with I/DD, extent of contact between the siblings, the quality of the sibling relationship, and family climate. Conversely, many characteristics have had mixed findings including: sibling gender, sibling order, the level of independence and/or maladaptive behaviors of individuals with I/DD, family size, and parent health. For instance, previous studies reported that female (vs. male) siblings were more likely to be sibling caregivers while Cuskelly (2016) reported no correlations regarding gender. Therefore, it is necessary to conduct additional research to identify the correlates of sibling caregiving.

Fourth, there seems to be a needed distinction between current and future sibling caregivers. Most studies did not distinguish between current and future caregivers; however, it seems that there may be differences between these two groups. For example, Burke and colleagues (2012) found that siblings were more likely to anticipate future caregiving when their parents were in excellent health. As such, it seems that siblings may not be able to accurately predict their caregiving roles. Further, 60% of siblings report anticipating living with their brothers and sisters; however, only 10% of siblings actually live with their brothers and sisters with I/DD (Freedman, Krauss, & Seltzer, 1997). To accurately identify correlates of sibling caregiving, it is necessary to look at current sibling caregivers.

This review had a few limitations. First, there were only 29 studies; most studies included small sample sizes which were primarily White, female, well educated, and middle-class. Further, most studies relied on convenience samples, potentially reflecting only the most involved siblings. Second, most studies used cross-sectional data. Thus, the results could not show the direction of any associations. Third, some studies relied on survey data collected via web-based surveys. Participants who were poorer, less educated, and from minority backgrounds may not have access to the internet. Another possible explanation is that people from different backgrounds may be connected with different supports and internet sources impacting their likelihood of hearing about sibling survey studies.

Implications for Research, Policy, and Practice

Only one study evaluated the effectiveness of an intervention (specifically, a future planning intervention, Heller & Caldwell, 2006). Understanding future planning could reduce caregiving burden for family caregivers and promote choice making for

individuals with I/DD (Heller & Caldwell, 2006). Further, siblings reported the need for support groups, workshops, and trainings for siblings and families (Heller & Kramer, 2009). There is a need to develop and test interventions for sibling caregivers to help resolve caregiving challenges.

Future research is also needed to examine the cultural influences of caregiving. In this review, sibling caregiving was examined across various countries. Despite their different geographic regions, most studies discussed similar challenges related to sibling caregiving. For example, common caregiving challenges included: the anxiety-inducing nature of caregiving roles, difficulty with service delivery systems, and the struggle to balance multiple responsibilities. In the future, researchers may consider examining the cultural impact on sibling caregiving based on geographic region.

Given that siblings face many caregiving demands and challenges, policymakers and practitioners need to offer supports to siblings to ameliorate such demands. Unfortunately, siblings are often overlooked in family support policies (Hodapp et al., 2005). For example, in the United States, the Family and Medical Leave Act (FMLA) allows eligible employees to take unpaid leave for up to 12 weeks to provide family caregiving. However, the FMLA does not mention siblings. In 2015, the Department of Labor updated their guidance about FMLA to specifically reference that siblings were eligible for unpaid leave in certain circumstances. However, there is still limited inclusion of siblings in the FMLA; perhaps correspondingly, employers may struggle to determine how to apply FMLA to siblings. Thus, there is an ongoing need to include siblings in family support policies.

Finally, families, including siblings, should conduct future planning. Unfortunately, families often do not conduct future planning (Freedman et al., 1997). Given the challenges among sibling caregivers, the longer lives of individuals with I/DD, and the aging population of parent caregivers, future planning is crucial. By gathering information about residence, employment, and medical supports, future planning can help ease caregiving burden (Heller & Caldwell, 2006). Practitioners should encourage families to engage in future planning.

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