

REVIEW

Sibling perceptions of living with a young person with Down syndrome or autism spectrum disorder: An integrated review

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Child/adolescent disability or chronic illness has a profound impact on families. Parents report increased stress, depression, disruptions in family functioning, and caregiver burden (Abbeduto et al., 2004; Al-Krenawi, Graham, & Gharaibeh, 2011; Hastings et al., 2005; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; O'Brien, Duffy, & Nicholl, 2009; Pelchat, Lefebvre, & Perreault, 2003), many times due to the young person's care requirements, interactions the youth has with family members, or the young person's behaviors. Siblings are also affected because relationships between brothers/sisters are unique due to their duration, egalitarian nature, and common cultural milieu. Sibling relationships also help children learn sociable behaviors, provide emotional and physical contact at critical life stages, and are usually the first/most intense/longest peer relation an individual will have. Consequently, when living with a young person with a disability, the effects on siblings may be different than if they live with a typically developing young person.

Specifically, effects on siblings range along a continuum and can be positive or negative (Cuskelly &

Abstract

Purpose. This integrative review synthesized current information from 28 research articles meeting inclusion criteria that examined sibling experiences when living with a young person with Down syndrome or autism spectrum disorder.

Conclusions. Five themes emerged related to sibling experiences: their knowledge of the condition, relationships with others, perceptions of the condition, emotional reactions to the situation, and behavioral/personality outcomes.

Practice Implications. Nurses caring for families raising youth with Down syndrome or autism spectrum disorder can enhance sibling development by providing individual interventions reflecting siblings' perceptions of the experience.

Gunn, 2006; Fleary & Heffer, 2013; Giallo, Gavidia-Payne, Minett, & Kapoor, 2012; Rossiter & Sharpe, 2001; Stoneman, 2005; Williams, 1997; Williams et al., 2009). Positive effects include greater empathy, independence, maturity, compassion, cooperation, understanding, helpfulness, self-control, kindness, improved self-esteem, and more positive interactions with others (Aksoy & Yildirim, 2008; Barak-Levy, Goldstein, & Weinstock, 2010; Dyke, Mulroy, & Leonard, 2009; Kaminsky & Dewey, 2001). Negative effects include depression, poor adjustment, increased sibling conflict and role tension, differential treatment, emotional/behavioral problems, anxiety, bitterness, resentment, alienation, guilt, fear, and decreased opportunity for peer contacts and activities outside the home, as well as being at higher risk of adjustment and other problems when compared with normative groups of siblings of typically developing children (TDC, which refers to those children who acquire a wide range of skills similar to most children their same age and living within the same culture; Children's Medical Services, 2012; Giallo &

Gavidia-Payne, 2006; Hastings, 2003; Houtzager et al., 2004; Meyer, Ingersoll, & Hambrick, 2011; Vermaes, van Susante, & van Bakel, 2012) or when compared with control groups of siblings of TDC (Barrera, Fleming, & Khan, 2004; Ishizaki et al., 2005).

While current research has improved understanding of sibling experiences, it is limited because much research is from the perspectives of parents/teachers rather than from the perspective of siblings themselves. In addition, there is little information discussing experiences and perceptions of siblings who live with youth with different disabilities as those experiences and perceptions may vary according to the type of disability. Therefore, the purpose of this integrated review was to address a gap in the literature by summarizing and synthesizing qualitative and quantitative studies examining sibling experiences from their own perspective when living with a young person with Down syndrome (DS) or autism spectrum disorder (ASD) rather than other developmental disorders, such as cerebral palsy, fetal alcohol syndrome, fragile X syndrome, or other intellectual disability. ASD and DS were selected because pediatric nurses are likely to care for these young people and their families in a variety of venues, including acute care facilities and in the community, as one in 68 youth has been identified with ASD (Centers for Disease Control and Prevention, 2014), and DS is the most commonly occurring chromosomal condition (National Down Syndrome Society [NDSS], 2014).

BACKGROUND

DS, a chromosomal abnormality, affects more than 400,000 people in the United States and is seen in one out of 691 births (NDSS, 2014). Young people with DS have varied intellectual capacities and similar physical features (Buckley, Bird, & Sacks, 2002; NDSS, 2014). DS accounts for approximately one third of moderate to severe cases of intellectual disability; however, the severity varies (Ferri, 2009), and most youth with DS have appropriate social skills (Buckley et al., 2002). DS has been discussed in disability research throughout the years, and early data suggested siblings were negatively impacted by living with a brother/sister with DS (Cuskelly & Gunn, 1993; McHale & Gamble, 1989). However, this view has shifted and more recent research suggests siblings are positively impacted by living with a child/adolescent with DS (Hodapp, 2007; Skotko & Levine, 2006).

ASD is a complex developmental disorders characterized by the early presence of persistent deficits in social interaction and communication across a number of different contexts and by repetitive, restricted behavior patterns, activities, or interests. Specifically, the *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition, notes these young people display deficits in nonverbal communicative behaviors and social-emotional reciprocity used for social interaction; have difficulties in understanding, maintaining, and developing relationships; display repetitive or stereotypical motor movements, unusual speech, and interests in sensory aspects of the environment or use of objects; and demonstrate the need for sameness, ritualized patterns of verbal/nonverbal behavior, inflexible adherence to routines, or show hyper- or hypo-reactivity to sensory input (American Psychiatric Association, 2013). Such deficits interfere with developing social relationships with family members (Autism Speaks, 2014), including siblings. Consequently, siblings may experience adjustment/coping difficulties, as well as impaired relationships with others (Smith & Elder, 2010). On the other hand, research also suggests positive effects on siblings. For example, some siblings exhibit less quarreling and competition, and greater admiration in their sibling relationships, than TDC (Mavropoulou & Baloyianni, 2007). Siblings also display more accepting and supportive behaviors, demonstrate enhanced psychosocial/emotional development and deep interpersonal perspectives, and assume adult responsibilities at an early age (Benderix & Sivberg, 2007).

Most data related to siblings of youth with DS and ASD are gathered from the perspective of parents and/or teachers and not as often from siblings. Therefore, this integrated review sought to synthesize published research studies where participants were siblings themselves rather than teachers or parents, so nurses caring for these young people can become aware of how they are affected by the experience.

METHODS

Following suggestions offered by Sandelowski, Voils, and Barroso (2006), this integrated review combined rather than separated analyses of qualitative and quantitative designs because our purpose was to synthesize findings from each design in order to “sum up” knowledge about sibling perceptions of their experiences living with a young person with ASD or DS. Therefore, following steps proposed by

Cooper (1982), we initially identified the problem as seeking to produce an integrative review that examined sibling perceptions when living with a young person with ASD or DS. Articles were then collected during a literature search using inclusion and exclusion criteria that identified qualitative, quantitative, and mixed-method designs focusing on the purpose of the review. Articles retrieved and selected were then summarized, analyzed, and synthesized. During interpretation, results from all articles were compared before categorizing/grouping similar results, and allowing themes and subthemes to be identified (Whittemore & Knafl, 2005), which were then organized and included in this review.

An experienced science librarian assisted the authors to ensure the search was comprehensive and focused on the purpose of the study by using Medline, CINAHL, PsycINFO, ERIC, and Family & Society Studies Worldwide. Search terms included *sibling, brother, sister, OR child, psychosocial OR psychologist*, adjust*, adapt*, experience, perce*, attitude, stress, cope, know*, learn** combined with the disabilities of interest: *Down syndrome, autism, autism spectrum disorder, ASD, Asperger's syndrome, and Pervasive Developmental Disorder (PDD)*. Reference lists of retrieved reports were also examined. Inclusion criteria included full-text empirical studies written in English and published between 2000 and 2014 to consider the most recent information. Sibling participants of youth with only either ASD or DS were between 4 and 21 years of age; if both parents and siblings participated in the study, only sibling data were extracted. Exclusion criteria included the following: books or book chapters, unpublished dissertations, published abstracts; sibling participants older than 21 years; if siblings could not be identified as living with a young person diagnosed with DS or ASD; if sibling perceptions could not be extracted from the data; results were reported for the family as a whole rather than siblings specifically; if examining outcomes of interventions for siblings; or if the youth with ASD or DS also had other developmental disabilities that may affect sibling perceptions.

RESULTS

The electronic search identified 277 articles for siblings of youth with DS and 1,348 articles for siblings of young people with ASD, autism, PDD, or Asperger's syndrome. After examining identified articles for inclusion criteria, 26 were selected for this review. However, one recently published and one in-press article by the authors were also included

because they met inclusion criteria, resulting in 28 articles selected for this review.

To assess validity, the 11 quantitative and 5 mixed-methods articles selected for the review were appraised at level IV (well-designed case-controlled and cohort studies) according to Melnyk and Fineout-Overholt (2011). The 12 qualitative articles were evaluated according to the guidelines for publication of qualitative research studies proposed by Elliott, Fischer, and Rennie (1999). Specifically, all of these 12 articles adequately described the sample, provided examples from interview data to support analysis decisions, described credibility checks, accurately reflected study purposes, and were well written. Most also provided information related to study limitations; however, few adequately described author values and assumptions related to study purposes (Elliott et al., 1999).

All articles were screened by study authors to determine if inclusion criteria were met by reading the article title and abstract, and/or the method section to determine how data were gathered, whom data were gathered from, if sibling data could be extracted from the data, and the age of sibling participants.

Studies meeting inclusion criteria were reviewed and organized into a table, including author, purpose, design, sample, method, and results (see Table 1). Participants came from a variety of countries, including the United States (13 publications), Australia (4 publications), Canada (3 publications), England/United Kingdom, Israel, and Belgium (2 publications each), and South Korea and Greece (1 publication each). Sample sizes varied according to study type: there were from 2 to 41 participants in the qualitative studies, from 25 to 119 in the quantitative studies, and between 30 and 205 in the mixed-methods studies.

Examination of the 28 studies discovered five themes describing sibling experiences and perceptions when living with a young person with DS or ASD. The themes included (a) knowledge of the condition (what they knew and who told them about the disability); (b) relationships with others (what their interactions were like with the young person with ASD or DS, family members, or those outside the family); (c) perceptions of the experience (how they viewed the situation); (d) emotional reactions (feelings, affect, reactions, or moods about the situation); and (e) behavioral/personality outcomes (social and academic effects). A discussion of these themes according to whether the sibling lived with a young person with DS or ASD follows.

Table 1. Summary of Included Studies

Author/country	Purpose	Design/level of evidence if quantitative	Sample	Method	Results
Angell and colleagues (2012) United States	To explore sibling experiences of individuals with autism and identify their support needs	Qualitative collective case study	12 siblings 6 females 6 males 7–15 years old Mean: 10.58	In-person semi-structured interviews	<ul style="list-style-type: none"> — Most strove for academic success, older siblings involved in youth's education — Socially competent but wanted more friends who understand youth — Assumed roles of caregivers, helpers, entertainers, "rescuers" — Were patient, forgiving — Recognized talents, strengths, needs of youth — Understanding of ASD increased with age — Sibling relationships: positive/negative — Youth's challenging, inappropriate behaviors embarrassing — Loved, proud of youth; concerned for youth's social acceptance and safety — Sadness when youth not accepted — Anxious about youth's future — Relationship depended on severity of autism — Accepted parental differential treatment — Knew about autism
Bachraz and Grace (2009) Australia	To explore sibling relationships when one child in the family has autism	Collective case study	3 female siblings 4–7 years Mean: 5.43 SD: .91	Semi-structured interview related to photographs taken by siblings	
Barak-Levy and colleagues (2010) Israel	To compare parent and sibling reports regarding sibling adjustment to living with a child with autism or TDC	Quantitative descriptive Level IV	27 siblings of children with ASD 15 females 12 males 6–18 years Mean: 12.51 27 siblings of TDC Matched for age and gender	WAI (Weinberger, 1996)	<ul style="list-style-type: none"> — Siblings of children with ASD: higher on helpfulness and responsibility than siblings of TDC
Baumann and colleagues (2005) United States	To explore what it means to be a sibling of a child with Down syndrome using Parse's theory of human becoming	Qualitative: descriptive exploratory	3 female siblings 9–10 years Mean: 10	Semi-structured interviews; art	<ul style="list-style-type: none"> — Saw child as just a boy — Experienced increased responsibility — Important to listen, understand child has feelings — Others see child as different

Table 1. Continued

Author/country	Purpose	Design/level of evidence if quantitative	Sample	Method	Results
Cuskelly and Gunn (2003) Australia	To examine relationships between siblings and the child with Down syndrome compared to siblings of TDC	Comparative; correlational mixed methods Level IV	54 siblings of children with DS 26 females 14 older Mean: 11.1 SD: 2.14 12 younger Mean: 10.9 SD: 2.33 28 male 14 older Mean: 10.6 SD: 1.68 14 younger Mean: 10.4 SD: 1.73 53 siblings of TDC 25 females 14 older Mean: 10.98 SD: 2.30 11 younger Mean: 10.61 SD: 2.46 28 males 14 older Mean: 10.86 SD: 1.86 14 younger Mean: 10.64 SD: 2.01	Sibling Inventory of Behavior (Shaefer & Edgerton, 1981) Interviews: caregiving chores; interactions with child with DS	— Siblings of child with DS: — More positive interactions than siblings of TDC — Less unkindness than siblings of TDC — If of same gender, more empathy than siblings of TDC — If assumed more caregiving, more positive sibling relationships — Caregiving related to empathy, involvement, and avoidance
Cuskelly and Gunn (2006) Australia	To examine the adjustment of siblings of a child with Down syndrome compared with adjustment of siblings of TDC	Comparative descriptive; mixed methods Level IV	53 siblings 7–14 years 25 female Mean: 11.08 28 male Mean: 10.67 53 siblings of TDC 25 female Mean: 10.92 28 male Mean: 10.75	Self-Perception Profile For Children (Harter, 1985) Interview: caregiving chores	— No differences between groups on competence and self-worth — Females: more satisfied with own behavior than males — Males: higher scores on athletic competence — Older: less satisfied with appearance and more caregiving — More caregiving if sibling of child with DS

Fisman and colleagues (2000) Canada	To compare adjustment of siblings of children with pervasive development disorder (PDD) , Down syndrome , and TDC across a 3-year span	Quantitative comparative Level IV	42 siblings of children with PDD 42 siblings of children with DS children 43 siblings of TDC 8–19 years old	The Survey Diagnostic Instrument (adapted from Child Behavior Checklist; Achenbach & Edelbrock, 1983) — Self-Perception Profile for Children (Harter, 1985) — Social Support Scale for Children (Harter, 1986) — Family Adaptability and Cohesion Evaluation Scale (FACES III; Olson, Porter, & Lavee 1985) — Sibling Relationship Questionnaire-Brief Version (SRQ; Furman & Buhrmeister, 1985) Semi-structured interview	— Siblings of children with PDD: More adjustment difficulties over time than siblings of children with DS or TDC
Graff and colleagues (2012) United States	To ascertain experiences of adolescent siblings of a child with Down syndrome who has additional health problems and increased caregiving demands	Qualitative descriptive	23 siblings 12 females 11 males 12–19 years Mean: 16 SD: 2.15	Semi-structured interview	— Focused more on fact child had DS rather than health problems requiring additional care — Noted family affected by child's caregiving needs — Learned acceptance, responsibility, viewed child as having easy personality
Hwang and Charnley (2010) South Korea	To use visual ethnography to explore siblings' experiences of living with a child with autism	Qualitative	9 siblings 5 females 4 males 7–15 years Mean: 11.2	Video diaries Home movies Interview	— Experienced shame and embarrassment — Did not speak openly of autism — Got used to strange behaviors — Experienced prejudice from others — Referred to autism as "sickness" or "illness"—most thought child would recover
Kaminsky and Dewey (2001) Canada	To investigate sibling relationships of children with autism compared with children with DS and siblings of TDC	Quantitative: comparative; correlational descriptive Level IV	30 siblings of CWA 30 siblings of CWDS 30 siblings of TDC 8–18 years Mean: 11	SRQ-Brief Version (Buhrmeister & Furman, 1990)	Siblings of children with DS — Higher levels of closeness/intimacy than other siblings Siblings of children with autism — Less prosocial behavior compared with siblings of children with DS Siblings of children with autism and DS — Greater admiration of child than siblings of TDC — Less quarreling and competition than siblings of TDC
Kaminsky and Dewey (2002) Canada	To investigate the psychosocial adjustment of siblings of children with autism compared with siblings of children with DS and TDC	Quantitative: comparative; correlational descriptive Level IV	30 siblings of CWA 30 siblings of CWDS 30 siblings of TDC 8–18 years Mean: 11–12	— Social Support Scale for Children (Harter, 1985) — Loneliness and Social Dissatisfaction Questionnaire (Asher, Hymel, & Renshaw, 1984)	Siblings of children with DS — More social support from close friends than siblings of TDC — More social support from classmates related to lower levels of loneliness Siblings of children with autism — More support from classmates/friends related to lower levels of loneliness — Sisters: higher social competence than brothers Siblings of children with autism and DS — Well adjusted; low levels of loneliness

Table 1. Continued

Author/country	Purpose	Design/level of evidence if quantitative	Sample	Method	Results
Lata and colleagues (2013) United States	To use photography to discover what is important in the lives of siblings of children with autism	Qualitative descriptive	14 siblings 5 females 9 males 8–16 years Mean: 10.79 SD: 2.29	Photography interview	— Often talked about positive characteristics of child
Macks and Reeve (2007) United States	To compare the psychosocial and emotional adjustment of siblings of children with autism and siblings of TDC	Quantitative; comparative; correlational descriptive Level IV	51 siblings of CWA 30 female 21 males 36 siblings of TDC 20 females 16 males	— Children's Depression Inventory-Short Form (Kovacs, 1992) — Piers-Harris Children's Self-Concept Scale (Piers, 1984)	— Demographic risk factors predicted psychosocial and emotional adjustment for siblings of children with autism — Siblings of children with autism : more positive self-concept than siblings of TDC
Mascha and Boucher (2006) Greece	To explore the subjective experiences and feelings of typically developing siblings with a brother or sister with autism	Qualitative descriptive	7–17 years 14 siblings 10 females 4 males Mean: 14.73 SD: 2.25 12 older 2 younger	Semi-structured interview	— Majority reported positive experiences— <i>noted</i> youth's good nature — Aggression, bad temper, embarrassment = most common difficulties — Discussed youth's behavior with parents — Learned about ASD from parents — Concerned about youth's future
Moyson and Roeyers (2011) Belgium	To describe and define the QOL of siblings of children with autism	Qualitative; phenomenology	17 siblings 10 females 7 males 6–14 years Mean: 10.41 SD: 2.26	Interview and focus groups	ASD is an invisible disease (child does not look different), which is challenging Themes: — Bothersome and negative behaviors — Difficulties communicating — Liked private times when alone — Worried about child — Accepted diagnosis and impact on sibling's life — Important to meet other siblings of children with autism — Need support/help from parents even though parents spent more time with child — Outside world often did not know about child — 36% reported depressive symptoms — Sisters: heightened depressive/anxiety compared to brothers
Orsmond and Seltzer (2009) United States	To examine the levels of depression and anxiety in adolescents who have a brother or sister with autism	Quantitative; comparative correlational Level IV	57 siblings 37 females 20 males 12–18 years Mean: 1.6 SD: 1.7	— Center for Epidemiological Studies-Depression scale (Radloff, 1977) — Revised Children's Manifest Anxiety Scale (Reynolds & Richmond, 1978) — Life events checklist from the NIMH Methods for Epidemiology of Child and Adolescent Mental Disorders (Lahey, Flagg, Bird, & Schwab-Stone, 1996)	

<p>Petalas and colleagues (2009) United Kingdom</p>	<p>To explore perceptions and experiences of TDC in middle childhood who had a brother with autism</p>	<p>Qualitative: Interpretive phenomenology analysis</p>	<p>8 siblings 5 females 3 males Mean: 11.19 SD: 1.32</p>	<p>Semi-structured interview</p>	<ul style="list-style-type: none"> — Negative impact of having a brother with ASD on themselves, families, and brother — Lives disrupted by peculiar/aggressive behavior; Impacted family recreational activities — Prejudice/misunderstanding from others — Felt angry, embarrassed, anxious — Accepted brother but some wished behavior would change — Had fun with, proud of brother — Efficative communication between parents and siblings facilitated adjustment — Turned to parent for information about ASD and support when upset
<p>Petalas and colleagues (2012) United Kingdom</p>	<p>To explore perceptions and experiences of adolescent siblings of a brother with autism</p>	<p>Qualitative: Interpretive phenomenology analysis</p>	<p>12 siblings 6 females 6 males 14–17 years Mean: 15.71 SD: 1.55</p>	<p>Semi-structured interview</p>	<p><u>Themes:</u></p> <ul style="list-style-type: none"> — Behaviors: negative, embarrassing, yet also some positive experiences — Others' reactions — Based appraisal of current situation on past — Accepted current situation — Worried about youth's future — Most well adjusted — Stressful experience — As siblings get older, formed "enhanced empathy" with child — Severity of autism negatively affects adjustment — Older siblings: more positive relationship than younger siblings
<p>Pilowsky and colleagues (2004) Israel</p>	<p>To explore the social and emotional adjustment of siblings of children with autism</p>	<p>Comparative descriptive mixed methods Level IV</p>	<p>30 siblings of children with ASD 18 females 12 males 6–15 years Mean: 9.72 SD: 2.65 28 siblings of children with mental retardation 16 males 12 females 6–15 years Mean: 9.91 SD: 2.63 30 siblings of children with developmental language disorders 14 males 16 females 6–15.59 years Mean: 9.12 SD: 2.58</p>	<p>WAI (Weinberger, 1996) Vineland Adaptive Behavior Scale—Social Domain (Sparrow, Balla, & Cicchetti, 1984) Interview</p>	<p>—</p>

Table 1. Continued

Author/country	Purpose	Design/level of evidence if quantitative	Sample	Method	Results
Pollard and colleagues (2013) United States	To examine typically developing adolescents' perceived relationship quality with siblings diagnosed with autism or Down syndrome	Quantitative: comparative correlational Level IV	119 sibs 81 sibs of CWA 38 sibs of CWDS Mean: 13.32 SD: 1.9	— Sibling domain of the Network of Relationships Inventory (Furman & Buhrmester, 1985) — Multidimensional Anxiety Scale for Children (March, Parker, Sullivan, Stallings, & Conners, 1997)	Siblings of youth with DS: greater relationship quality than siblings of children with autism Siblings of youth with autism: — Fewer social support qualities, more negative interchanges — Greater anxiety, low relationship quality compared with siblings of youth with DS Siblings of youth with DS and autism: — Negative interchanges related to higher levels of anxiety — Child with DS: most common family member photographed: d/t positive characteristics
Rampton and colleagues (2007) United States	To use photography to answer what is important to siblings of children with Down syndrome To determine if there are differences in photographs according to sibling age and gender	Qualitative descriptive	16 siblings 10 females 6 males 7–15 years Mean: 10.21	Photography interview	
Rivers and Stoneman (2008) United States	To examine associations between sibling perceptions of differential parenting and the quality of the sibling relationship with a child with autism	Quantitative: correlational Level IV	50 siblings: 25 females 25 males 7–12 years Mean: 9.7 40 older	— Sibling Inventory of Behavior (Shaefer & Edgerton, 1981) — Satisfaction with the Sibling Relationship (McHale & Gamble, 1989)	— When dissatisfied with differential parenting, quality of sibling relationship is compromised
Ross and Cuskelly (2006) Australia	To examine commonly experienced stressors of siblings of children with autism To examine coping strategies that siblings of children with autism use to deal with these situations	Quantitative: descriptive Level IV	25 siblings 6 females 19 males 8–15 years Mean: 10.64 SD: 2.33	— Knowledge of Autism/Asperger's syndrome (KAAS; Ross & Cuskelly, 2006) — KIDCOPE (Spirito, Stark, & Williams, 1988)	— Reasonable knowledge of ASD — Aggression of child: most common stressor — Felt sad/angry — Did not use blame as a coping strategy
Sage and Jegatheesan (2010) United States	To examine TDC perceptions of their siblings with autism and their relationships with them in a European American and Asian American family	Qualitative: descriptive	2 male siblings 7 years	4 semi-structured interviews using a draw-and-tell technique Video-recorded observations of siblings at play	Differences in perceptions: — European American: good understanding of autism; close relationship; saw young person as special/unique; had fun together — Asian American: not well informed; said young person had poor listening skills and short attention span; feels angry/frustrated but wears a smile around his brother/sister
Skotko and colleagues (2011) United States	To examine siblings' feelings and perceptions toward child with Down syndrome	Mixed methods Level IV	205 siblings 9–11 years Mean: 10.6 SD: 1.6	Three-page questionnaire including open-ended questions and a series of Likert statements developed by authors	— Affectionate toward child — Proud of child especially if of same gender — Felt sad if child had learning difficulties — Worried how child teased by others — Felt comfortable telling other people brother/sister has DS — Comfortable asking parents about DS — Most planned to remain involved in child's life

Van Riper (2000) United States	To examine sibling well-being in families raising a child with Down syndrome	Correlational mixed methods Level IV	41 siblings 23 females 18 males 7–18 years Mean 11.46 SD: 3.15	— Piers-Harris Children's Self-Concept Scale (Piers, 1984) Interview	— Above average self-concept — Child taught patience, love, happiness, acceptance, courage to stick with things
Verre and colleagues (2003) Belgium	To investigate the psychological adjustment of siblings of children with autism compared with TDC	Quantitative: comparative Level IV	29 siblings of children with ASD 12 females 17 males 6–16 years Mean: 11.14 SD: 3.23 29 siblings of TDC 12 females 17 males 6–16 years Mean: 11.31 SD: 3.29	— Dutch version of the Matson Youngsters (Matson, Rotatori, & Helsel, 1983; Prins, 1997) — Dutch version of the Self-Description Questionnaire I and II (SDQ-I and SDQ-II; March, 1998; Verre & Roeyers, 1998)	— Sisters (12–16 years): higher social competence and more positive self-concept compared with siblings of TDC — Siblings of youth with ASD: more behavioral problems than siblings of TDC
Ward and colleagues (in press) United States	To learn from siblings their perception of life with a young person who has autism spectrum disorder To examine interviews for differences according to sibling age, birth order, and gender	Qualitative: descriptive	22 siblings of youth with ASD 11 females 11 males	Interview	— Recognized difficult and positive aspects of living with a young person with ASD — <u>Younger siblings</u> : reflected on childhood experiences, wished could play together; mentioned what young person could do — <u>Adolescent siblings</u> : learned life lessons from experience, talked about life changes when ASD was diagnosed; seemed introspective/protective toward the young person with ASD — <u>Brothers</u> : wished played more often; frequently mentioned aggressive behaviors — <u>Sisters</u> : focused on relationship and communication difficulties

Note: ASD, autism spectrum disorder; CWA, child with autism; CWDS, child with Down syndrome; DS, Down syndrome; NIMH, National Institute of Mental Health; SD, standard deviation; TDC, typically developing children; WAI, Weinberger Adjustment Inventory.

Sibling perceptions of living with a young person who has DS

Knowledge. Two studies discussed siblings' knowledge of DS. One discovered siblings learned about DS from parents, healthcare professionals, or their own research (Graff et al., 2012). The other reported siblings lacked knowledge and wanted additional information regarding DS (Skotko & Levine, 2006).

Relationships with others. Living with a young person with DS impacted siblings' relationships with others, including the young person, parents/family members, and peers/classmates. Siblings reported positive relationships with the youth, viewed the relationship as an important part of their life (Baumann, Dyches, & Braddick, 2005; Kaminsky & Dewey, 2001), and enjoyed the time spent together (Graff et al., 2012). Other investigators discovered siblings loved and cared about the youth with DS, took pride in the brother/sister's accomplishments (Skotko & Levine, 2006), and were more understanding, admired the young person more (Kaminsky & Dewey, 2001), or had a greater overall sibling relationship quality (Pollard, Barry, Freedman, & Kotchick, 2013) than siblings of young people with ASD or TDC. Cuskelly and Gunn (2003, 2006) noted these siblings also reported more positive interactions with and less unkindness toward the youth with DS than siblings living with TDC, did not usually avoid interactions, and as they got older provided more care.

Brothers/sisters also reported that their relationship with parents and friends was impacted by the situation; parents were more lenient and gave extra attention and care to the young person with DS (Graff et al., 2012; Skotko & Levine, 2006). Siblings also thought living with a child/adolescent with DS increased family togetherness (Graff et al., 2012), and felt quality time and fairness were important by ensuring strong relationships with parents (Cuskelly & Gunn, 2003, 2006; Skotko & Levine, 2006). Finally, Kaminsky and Dewey (2002) discovered these siblings reported receiving higher levels of social support from close friends compared with siblings of young people with ASD; higher levels of social support from classmates were also related to less loneliness in these siblings.

Perceptions. Siblings living with a child/adolescent with DS often perceived the young person positively. In fact, some siblings viewed the

young person as "just a boy" (Baumann et al., 2005). Other investigators noted these siblings admired the child/adolescent more than did siblings of children/adolescents with autism or TDC (Kaminsky & Dewey, 2001). Interestingly, siblings often emphasized positive rather than negative experiences during interviews and focused more on the DS rather than health problems requiring additional care; many viewed the youth as having an easy personality; and living with the young person was amazing, fun, and inspiring (Graff et al., 2012). Finally, the most common photographs of family members taken by siblings were of the child/adolescent with DS, and when discussing these photographs siblings noted the youth's positive personality characteristics (Rampton et al., 2007).

Emotional reactions. Siblings also displayed emotional reactions to the experience. For example, some siblings reported being frustrated and angry when experiencing communication difficulties or dealing with demanding/destructive behaviors (Graff et al., 2012). Skotko, Levine, and Goldstein (2011) found siblings were sad if the young person had learning disabilities and worried about the brother/sister when teased by others. On the other hand, Cuskelly and Gunn (2003) discovered that siblings of young people with DS were empathetic.

Behavioral/personality outcomes. For the most part, living with a young person with DS positively influenced siblings' behaviors and personality outcomes. For example, siblings noted they developed personal strengths, including increased levels of caring and kindness (Cuskelly & Gunn, 2003), more helpful attitudes (Skotko & Levine, 2006), and greater patience and acceptance (Graff et al., 2012; Van Riper, 2000). The experience also required they be more involved in the child/adolescent's life and assume more caregiving responsibilities (Baumann et al., 2005; Cuskelly & Gunn, 2003; Graff et al., 2012; Skotko & Levine, 2006), especially if they were older (Cuskelly & Gunn, 2006). In addition, siblings reported doing more chores around the house than their mothers acknowledged (Cuskelly & Gunn, 2006) and self-reported they had above-average self-concepts (Van Riper, 2000). However, Cuskelly and Gunn (2006) found no differences in self-worth and competence when self-reports of siblings of a young person with DS were compared with siblings not raised with a young person with

a disability. Finally, Fisman, Wolf, Ellison, and Freeman (2000) discovered these siblings had less adjustment difficulties over time than siblings of children/adolescents with PPD.

Sibling perceptions of living with a young person who has ASD

Knowledge. Siblings of youth with ASD reported knowing about ASD (Ross & Cuskelly, 2006), but Sage and Jegatheesan (2010) discovered it depended on the family ethnicity. Other investigators found siblings knew about personality characteristics and traits associated with ASD (Angell, Meadan, & Stoner, 2012; Bachraz & Grace, 2009) and accepted the diagnosis and the impact it had on the youth (Moyson & Roeyers, 2011). As siblings aged, their knowledge and understanding of the young person and his/her behavior deepened (Angell et al., 2012). Even though some siblings described ASD as a sickness or illness making communication and appropriate conduct difficult, they also believed recovery was possible (Hwang & Charnley, 2010). However, Moyson and Roeyers (2011) found siblings viewed ASD as an invisible disease because the brother/sister did not look different.

Siblings learned about ASD primarily from parents, and when they wanted to know more about ASD often sought out parents for information (Petalas, Hastings, Nash, Dowey, & Reilly, 2009). However, how much information parents shared varied. Some parents openly discussed ASD (Mascha & Boucher, 2006), whereas others did not (Sage & Jegatheesan, 2010).

Relationship with others. Relationships with the young person, parents, and friends were impacted by ASD. Siblings reported positive/negative qualities about their relationship with the child/adolescent, but often it depended on the presence or absence of communication difficulties (Moyson & Roeyers, 2011; Ward, Smith, Mandleco, Dyches, & Freeborn, in press), or the severity of the ASD; it was better if the ASD was less severe (Bachraz & Grace, 2009). In addition, siblings loved and learned from the child/adolescent, enjoyed the relationship (Angell et al., 2012; Latta et al., 2013; Sage & Jegatheesan, 2010; Ward et al., in press), and shared a special bond (Petalas et al., 2009). Older siblings described the relationship they had with the youth more positively than younger siblings (Pilowsky, Yirmiya, Doopelt, Gross-Tsur, & Shalev, 2004; Ward et al., in press).

However, ASD was also stressful on the sibling relationship because of aggressive/disruptive behaviors (Mascha & Boucher, 2006; Petalas et al., 2009; Ward et al., in press). These negative behaviors resulted in limited interactions between siblings and the child/adolescent with ASD (Petalas et al., 2009; Petalas, Hastings, Nash, Reilly, & Dowey, 2012; Sage & Jegatheesan, 2010), and at times caused resentment (Hwang & Charnley, 2010; Petalas et al., 2009). Siblings also reported themselves as having more negative interchanges and lower levels of relationship quality than did siblings of youth with DS (Pollard et al., 2013), and demonstrated less prosocial behaviors, intimacy, and nurturance toward the youth with ASD when compared with siblings of youth with DS (Kaminsky & Dewey, 2001).

ASD also impacted relationships with parents. Siblings reported they felt less noticed by parents because the young person required much attention, but also they would seek out parents for help when they needed support (Moyson & Roeyers, 2011; Petalas et al., 2009; Ward et al., in press). On the other hand, some siblings accepted parental differential treatment (Bachraz & Grace, 2009). However, if not satisfied with differential treatment, the quality of their relationship with the young person was compromised (Rivers & Stoneman, 2008).

Siblings noted those outside the family often did not know about the situation (Moyson & Roeyers, 2011); others reported being teased by peers and felt socially awkward and rejected (Petalas et al., 2009, 2012), resulting in social withdrawal (Petalas et al., 2009; Ross & Cuskelly, 2006). Other siblings said having a brother or sister with ASD negatively affected their relationship with friends (Hwang & Charnley, 2010), and some reported experiencing prejudice and misunderstanding (Petalas et al., 2009). Consequently, siblings did not talk openly about ASD with friends (Hwang & Charnley, 2010); however, Moyson and Roeyers (2011) learned siblings thought it was important to meet other brothers/sisters of youth with ASD.

Perceptions. Sibling perceptions varied along a continuum. Many viewed the youth negatively and said the experience was stressful (Pilowsky et al., 2004). They considered the aggressive behaviors disruptive (Moyson & Roeyers, 2011; Petalas et al., 2009; Ross & Cuskelly, 2006; Ward et al., in press) and embarrassing (Mascha & Boucher, 2006; Petalas et al., 2012), especially in public places (Angell et al., 2012). However, some siblings reported the

situation was not always negative because they learned from the experience (Petalas et al., 2009; Ward et al., in press), admired (Kaminsky & Dewey, 2001) and were proud of the young person's efforts and achievements (Angell et al., 2012; Petalas et al., 2009), reported positive aspects of the experience (Mascha & Boucher, 2006; Petalas et al., 2012), and believed time spent together was fun (Sage & Jegatheesan, 2010). In fact, when discussing photographs they took of the youth with ASD, siblings noted positive characteristics (Latta et al., 2013). However, some siblings worried about the young person's future, were concerned about safety, and were aware of the sense of responsibility they felt for the brother/sister (Angell et al., 2012; Mascha & Boucher, 2006; Moyson & Roeyers, 2011; Petalas et al., 2012; Ward et al., in press).

Emotional reactions. Siblings experienced several emotions associated with living with a young person with ASD. These included anxiety (Orsmond & Seltzer, 2009; Petalas et al., 2009), especially when they perceived themselves as having lower sibling relationship quality (Pollard et al., 2013); anger (Petalas et al., 2009; Ross & Cuskelly, 2006); and embarrassment related to the youth's aggressive/disruptive behaviors (Angell et al., 2012; Hwang & Charnley, 2010; Mascha & Boucher, 2006; Petalas et al., 2009). However, other siblings were less anxious than those not living with a young person with ASD (Macks & Reeve, 2007). Some siblings felt sorry for the child/adolescent, most often when the young person was not accepted by others (Angell et al., 2012), and sisters reported increased levels of depression (Orsmond & Seltzer, 2009). On the other hand, Macks and Reeve (2007) learned these siblings were empathetic, and Pilowsky and colleagues (2004) noted that as siblings aged they formed "enhanced empathy." Finally, Kaminsky and Dewey (2002) reported these siblings were less lonely if they received high levels of social support from friends and classmates.

Behavioral/personality outcomes. Even though siblings experienced positive/negative behavioral/personality outcomes when living with a brother or sister with ASD, and most were well adjusted, the severity of ASD affected sibling adjustment (Pilowsky et al., 2004). Positive outcomes included improved self-concept, empathy, and less anxiety than those not living with a child/adolescent with ASD (Macks & Reeve, 2007; Verte, Roeyers, & Buyesse, 2003). These siblings also scored them-

selves higher on helpfulness and responsibility than siblings of TDC (Barak-Levy et al., 2010), and adjusted to and accepted the disability and behaviors (Hwang & Charnley, 2010; Petalas et al., 2009). However, adjustment was facilitated by learning about ASD, open communication with parents (Mascha & Boucher, 2006; Petalas et al., 2009), and through interactions with supportive peers, parents, typically developing siblings, and professionals (Petalas et al., 2009). Negative outcomes included becoming quiet and withdrawn to avoid explaining poor behaviors (Petalas et al., 2009) and viewing increased responsibility at home negatively (Mascha & Boucher, 2006; Petalas et al., 2009). However, Angell and colleagues (2012) learned most siblings of youth with ASD worked to achieve academic success, and Fisman and colleagues (2000) discovered that over time, siblings of youth with PPD experienced more adjustment difficulties than siblings of youth with DS or TDC.

DISCUSSION

This review sought to synthesize research published between 2000 and 2014 on the experiences of siblings between 4 and 21 years of age growing up with a young person with DS or ASD, from the siblings' perspectives. Analysis suggests there are similarities and differences in sibling perceptions according to their knowledge of the condition, how the situation affects their relationships with others, their perceptions of the condition, their emotional reactions to the experience, and their behavioral/personality outcomes. A discussion of these perceptions follows.

Even though siblings of youth with ASD seemed to know more about the disability than siblings of youth with DS (Angell et al., 2012; Bachraz & Grace, 2009; Ross & Cuskelly, 2006), their knowledge depended on family ethnicity (Sage & Jegatheesan, 2010) and age (Angell et al., 2012; Ward et al., in press). However, some siblings of youth with ASD did not fully understand the disability and thought recovery was possible (Hwang & Charnley, 2010), or viewed ASD as an invisible disease because the child/adolescent did not look different (Moyson & Roeyers, 2011).

Siblings of youth with ASD or DS learned about the disability from parents (Graff et al., 2012; Mascha & Boucher, 2006; Petalas et al., 2009; Ross & Cuskelly, 2006; Sage & Jegatheesan, 2010). Yet how much siblings of youth with ASD learned or were taught depended on family ethnicity (Sage & Jegatheesan, 2010), whereas the effect of ethnicity

on perceptions of siblings of youth with DS was not discussed in articles reviewed. On the other hand, even though some siblings of young people with DS learned about DS from healthcare professionals and personal research (Graff et al., 2012), others wanted to know more about the condition (Skotko & Levine, 2006). There was no information in articles reviewed about whether or not siblings of youth with ASD learned about ASD from healthcare professionals.

Living with a young person with DS or ASD affected relationships with others, including the youth, parents, and friends. Both groups loved (Angell et al., 2012; Graff et al., 2012; Sage & Jegatheesan, 2010; Skotko & Levine, 2006; Ward et al., in press) and were proud of the young person (Hwang & Charnley, 2010; Petalas et al., 2009; Skotko & Levine, 2006). However, siblings of youth with ASD more frequently reported the disability was stressful and negatively impacted their relationship with the child/adolescent, often because of the young person's behaviors (Hwang & Charnley, 2010; Mascha & Boucher, 2006; Petalas et al., 2009; Sage & Jegatheesan, 2010; Ward et al., in press) than siblings of youth with DS. Siblings also demonstrated less prosocial behaviors, intimacy, and nurturance toward the youth with ASD when compared with siblings of youth with DS (Kaminsky & Dewey, 2001). Both groups also reported receiving less attention from parents (Petalas et al., 2009; Skotko & Levine, 2006; Ward et al., in press), but siblings of youth with DS felt parents were more lenient toward the young person (Graff et al., 2012; Skotko & Levine, 2006), yet also thought the experience increased family togetherness (Graff et al., 2012). Finally, siblings of young people with ASD reported that ASD negatively impacted their interactions with friends (Hwang & Charnley, 2010; Petalas et al., 2009; Ross & Cuskelly, 2006), whereas siblings of youth with DS did not experience different relationships with friends compared with siblings of TDC (Cuskelly & Gunn, 2003), and received higher levels of social support from close friends compared with siblings of youth with ASD (Kaminsky & Dewey, 2002).

There were differences in sibling perceptions when living with a young person with ASD or DS. Specifically, siblings of youth with DS frequently mentioned positive perceptions of the young person (Baumann et al., 2005; Graff et al., 2012; Kaminsky & Dewey, 2001), whereas siblings of a young person with ASD often noted both positive (Angell et al., 2012; Kaminsky & Dewey, 2001, 2002; Mascha &

Boucher, 2006; Petalas et al., 2009, 2012; Ward et al., in press) and negative (Angell et al., 2012; Mascha & Boucher, 2006; Moyson & Roeyers, 2011; Petalas et al., 2009, 2012; Pilowsky et al., 2004; Ross & Cuskelly, 2006) perceptions. Most commonly, negative perceptions of siblings living with youth with ASD related to aggressive or destructive behaviors.

Siblings of young people with ASD or DS reported varying emotional reactions. Many siblings from both groups reported negative emotional reactions, including anger, anxiety, embarrassment, depression, and sadness (Angell et al., 2012; Graff et al., 2012; Hwang & Charnley, 2010; Mascha & Boucher, 2006; Orsmond & Seltzer, 2009; Petalas et al., 2009; Ross & Cuskelly, 2006; Skotko & Levine, 2006; Ward et al., in press). On the other hand, both sibling groups also displayed positive emotional reactions to the experience; the most commonly mentioned positive emotional reaction was empathy (Cuskelly & Gunn, 2006; Macks & Reeve, 2007; Pilowsky et al., 2004).

Finally, living with a young person with DS or ASD affected siblings' behaviors and personality outcomes. Specifically, both groups had better self-concepts than siblings of TDC (Macks & Reeve, 2007; Van Riper, 2000); displayed higher levels of caring, kindness, and helpfulness (Barak-Levy et al., 2010; Cuskelly & Gunn, 2003; Skotko & Levine, 2006); became patient and accepting (Graff et al., 2012; Van Riper, 2000; Ward et al., in press); and assumed increased responsibilities at home (Baumann et al., 2005; Graff et al., 2012; Mascha & Boucher, 2006; Petalas et al., 2009; Skotko & Levine, 2006; Ward et al., in press). On the other hand, some siblings of youth with ASD viewed increased responsibilities negatively (Barak-Levy et al., 2010; Mascha & Boucher, 2006; Petalas et al., 2009).

IMPLICATIONS

Improving sibling knowledge of ASD and DS is essential. Therefore, it is critical that nurses working with families raising a young person with ASD or DS be aware of sibling knowledge, and provide information as needed, clarify misunderstandings, and answer questions honestly. Nurses also need to support parents as they talk to siblings about DS or ASD, provide them with age-appropriate materials to share with siblings, and if parents are uncomfortable talking with siblings nurses should learn why and assist them to become more comfortable. Although all siblings reported assuming more

responsibilities, parents need to be careful they are not asked to assume more responsibilities than what is reasonable, and explain why siblings may sometimes need to assume these responsibilities. However, since parents are perceived as spending more time with the youth than with the sibling, they should be encouraged to also spend quality time with siblings.

If siblings display negative emotions to the situation, it would be important to help siblings understand that these reactions are common, and then implement preventative interventions, such as information sessions and sibling support groups (Bloch & Weinstein, 2010). Since many behavioral and personality outcomes seen in these siblings are positive, these outcomes should be encouraged. Nurses also need to be aware that the relationships these siblings develop with others are affected by the situation. Therefore, strategies such as support for preventing or dealing with challenging behaviors, teaching siblings how to use positive behavior interventions, and engaging in developmentally appropriate play may be useful. Since sibling relationships with friends were affected by the situation, nurses should encourage them to develop positive relationships with other young people, especially those also living with a child/adolescent with ASD or DS, as sharing thoughts and feelings with others in the same situation can be helpful (Packman et al., 2005; Rintala, Jaatinen, Paavilainen, & Åstedt-Kurki, 2013). Negative relationships with friends may occur because friends do not understand sibling experiences. Consequently, nurses could help siblings share information with friends about their brother/sister so they become more understanding.

CONCLUSION

Clearly, living with a child/adolescent who has either DS or ASD disability is life-changing for siblings; many adapt to the situation, whereas others are continually challenged and have difficulties. Specifically, siblings of both groups primarily learned about ASD or DS from parents. However, siblings of youth with ASD knew more about ASD than siblings of youth with DS knew about DS. The experience also affected relationships with others, and both groups noted parents paid more attention to the youth than parents paid to the siblings. However, siblings of youth with DS tended to perceive the youth with DS

more positively than siblings of young people with ASD. Finally, both groups reported similar emotional reactions to the experience and noted positive behavioral and personality outcomes for themselves.

Even though this review fills a gap in the literature and suggests sibling perceptions exist along a continuum, there are limitations. Studies examined were primarily cross-sectional rather than longitudinal and published between 2000 and 2014. In addition, studies represented diverse research questions, used different methodologies, obtained data through questionnaires or interviews, and used participants living in eight countries, between 4 and 21 years of age. However, no information was provided on the articles synthesized as to how seriously the young person was affected with ASD or DS. In addition, some articles reviewed appeared to use the same sample (Cuskelly & Gunn, 2003, 2006; Kaminsky & Dewey, 2001, 2002; Petalas et al., 2009, 2012), and four of the authors' articles (Graff et al., 2012; Latta et al., 2013; Rampton et al., 2007; Ward et al., in press) were evaluated. Although different samples and methods were used in each of these articles, bias was still possible. Therefore, generalizations are limited and further research is warranted.

Future research should continue exploring sibling perceptions from their own perspective. Specifically, it would be important to gather data from siblings of youth with DS or ASD with different demographic characteristics (family type, ethnic background, socioeconomic status, educational levels) and then compare perceptions across variables. Triangulating data by investigating parents' perceptions regarding sibling experiences and then comparing their responses with those of siblings may also be useful. In addition, gathering information from siblings living in different geographical areas or more thoroughly examining differences in perceptions according to birth order, age, and gender might add to our understanding of sibling perceptions. Further recommendations include using siblings living with TDC or siblings of young people with other chronic conditions/disabilities as participants so comparisons are possible, and carefully examining siblings with positive perceptions in order to help explain why some siblings have fewer difficulties than others in adjusting to the situation. Finally, it would also be important to gather information longitudinally and consider how seriously the ASD or DS affected the young person.

How might this information affect nursing practice?

Nurses interacting with families raising youth with DS or ASD often focus on the young person and/or parents rather than on siblings. Often labeled the “forgotten child,” siblings are often affected by the situation and exposed to more parental stress/anxiety/irritability than brothers/sisters raised with typically developing youth. Consequently, nurses should understand sibling experiences and provide appropriate interventions to these families. Specifically, it is important to provide siblings with information related to the disability, as needed, especially if the youth has ASD. Research suggests siblings have positive relationships with the youth, yet siblings of youth with ASD more frequently reported the young person’s behaviors were stressful and negatively impacted relationships with others. Therefore, providing support to prevent/deal with challenging behaviors and teaching siblings how to use positive behavior interventions may be helpful. Parents should be reminded to be careful siblings are not asked to assume more responsibilities than what is reasonable. Since siblings of youth with ASD or DS reported positive and negative emotional reactions to the experience, they may need assistance understanding that negative emotional reactions are common; information sessions and sibling support groups may be helpful. Nurses can also encourage parents to spend time with siblings discussing their experiences, allaying fears/worries, and helping brothers/sisters understand how they might channel these emotions to become less negative. Since many behavioral and personality outcomes seen in siblings of youth with DS or ASD are positive, these outcomes should be encouraged.

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