

Siblings of people with intellectual and developmental disabilities: a systematic review on their quality of life perceptions in the context of a family

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Background: Within Family Quality of Life (FQoL) research, perceptions of siblings of people with intellectual and developmental disabilities (IDD) in the setting of a family are limited studied. The aim of this systematic review is to find relevant information about quality of life perceptions of siblings of people with IDD. Two main questions guided this review: (1) what are the siblings' perceptions on quality of life in the context of their family? (2) what needs and challenges do siblings have regarding their quality of life as siblings of individuals with IDD? **Methods:** A systematic search was conducted using Scopus, PsycInfo, ERIC and Web of Science databases, involving keywords and combinations such as Intellectual and Developmental Disabilities, Family Quality of Life and siblings. **Results:** We identified a total of 48 articles. Analysis showed siblings' diverse perceptions of quality of life and their multiple experiences, needs, desires and concerns. **Conclusions:** Results contribute to knowledge about the quality of life and well-being of siblings of all ages. Suggestions for support, interventions and future research are given, such as the necessity of educating local communities regarding siblings' needs, the study of siblings' experiences in different cultural contexts or the importance of conducting research with clear theoretical frameworks and focused on the multiple components that might be influencing siblings' quality of life.

Keywords: siblings, quality of life, family quality of life, intellectual and developmental disability, systematic review

Introduction

Families provide a context where individuals can develop and influence each other. As defined by Poston *et al.* (2003), “a family includes the people who think of themselves as part of the family, whether related by blood or marriage or not, and who support and care for each other on a regular basis” (p. 319). Given the dynamic and interactive nature of families, any situation regarding one of the family members has the potential to affect the other members and, eventually, the whole system (Zuna *et al.* 2010). Thus, the presence of a disability could influence the quality of life of the family and of its individual members (Poston *et al.* 2003).

Over the past two decades, the construct of family quality of life (FQoL) has been largely studied regarding conceptual, theoretical and measurement aspects (see Boelsma *et al.* 2017, Brown *et al.* 2006). Zuna, *et al.* (2009) defined FQoL as a “dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact.” (p. 262). Individuals' quality of life and FQoL convey and interact in a continuous manner influencing each other. Consequently, it is difficult to separate the reported quality of life of a single member from the general overview of FQoL (Boelsma *et al.* 2017). The instruments used to date had primary looked at FQoL from a parent's and, particularly, mother's point of view, while the voices of other family members have been usually overlooked (Vanderkerken *et al.* 2018). As mothers responses in representation of the whole family had been worthy considered (e.g. Chiu *et al.* 2017, Samuel

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et al. 2018) this is the same with siblings. With a focus on siblings' perceptions it becomes more clear that every member of the family has its own perceptions regarding quality of life, with all of them deserving to be explored (as it is recently happening with fathers [see Schippers *et al.* 2020]). Therefore, the present review is focused on siblings' quality of life; this is the perceptions and well-being of being a sibling in a certain family.

Siblings and quality of life in the literature

Studies from the FQoL field have reported that siblings have specific needs and concerns regarding their quality of life that may differ from those expressed by their parents and from the general FQoL perceptions (Luijckx *et al.* 2016). For example, young siblings appreciate having specific information about their brother's or sister's disability and supportive friends with whom they are able to share their experiences (Moysen and Roeyers, 2011). Further, sibling's quality of life's perceptions change along the years due to the multiple and significant roles siblings play in the lives of their brothers and sisters with and without intellectual and developmental disabilities (IDD) (Tozer *et al.* 2013).

Research has provided important information on siblings' experiences regarding their particular family situation, such as the long-lasting nature of sibling relationships or the recognition that these relationships constitute a source of self-development and joy for both siblings (Stoneman 2005). The rising number of siblings who are embracing the role of carers of their brothers and sisters as a result of an increased life expectancy of people with IDD, has led to an enlargement of siblings' literature (Heller and Kramer, 2009). Many authors have been interested in siblings and their experiences with a considerable disparity of approaches and focus of interest, while their research's theoretical frameworks were not always explicit (see Stoneman 2005, for an overview).

Systematic reviews about siblings have explored their experiences, relationships or the influence that having a brother or a sister with a disability have had in their life. However, much less is known about their quality of life perceptions. For instance, previous reviews have shown that outcomes on siblings' well-being and siblings' experiences seem to be ambivalent and diverse (Orsmond and Seltzer, 2007). The meta-analysis by Rossiter and Sharpe (2001) indicated that it is not clear to what extent having a brother or a sister with a disability influences the siblings' life. Blacher *et al.* (2005)' review about families with a member with ID, detected differences in the adjustment and attachment styles of siblings while Heller and Arnold (2010) noted that influences on siblings' personal well-being were either positive and negative depending on different variables like the closeness of the siblings' relationship or the level of involvement in the siblings' life.

Nevertheless, while these reviews provided a valuable insight into siblings' reality, none of them had sibling's quality of life' perceptions as the main focus of their research nor their reported findings. That's why, in this systematic review, siblings' quality of life perceptions will be explored, as they constitute an essential but sometimes forgotten part of family life. Therefore, the focus is not on siblings' individual quality of life but on their quality of life as siblings in a family context. From the multiple identities an individual could hold, we took the one that refers to the specific place this individual is occupying inside a family; in this case, a sibling of a person with IDD.

Aim of the present systematic review

The aim of this study is to provide a more systematic review by exploring the perceptions of quality of life of siblings of people with intellectual and developmental disabilities available in the more recent literature. Two main questions guided this review: (1) what are the siblings' perceptions on quality of life in the context of their family? (2) what needs and challenges do siblings have regarding their quality of life as siblings of individuals with IDD?

Methods

Authors followed the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines by Liberati *et al.* (2009) regarding the search strategy, application of eligibility criteria, selection of included studies, data extraction, data analysis and quality assessment.

Search strategy

A keyword search strategy was conducted in May 2019 for the period 2003–2019 and actualized in December 2021, using the following specialized databases: Scopus, Web of Science (WoS), Education Resources Information Center (ERIC) and PsycInfo. Keywords related with quality of life, such as family quality of life, health-related quality of life, outcome and well-being were matched with keywords related to people with IDD such as intellectual or developmental disabilities, mental retardation¹ and learning disabilities². It is noted that developmental disabilities such as autism were included (but not high functioning autism). These words were also matched to those related with siblings: brothers, sisters and 'brothers and sisters'. Truncated keywords term *disab** and *famil** plus 'quality of life' were likewise used to increase the chance of retrieving relevant articles. Between search terms, AND was used as a Boolean operator. The reference lists of some selected articles, together with the published article index of relevant journals in the field, were searched manually ($n = 30$). Finally, 48 articles were included in the qualitative synthesis.

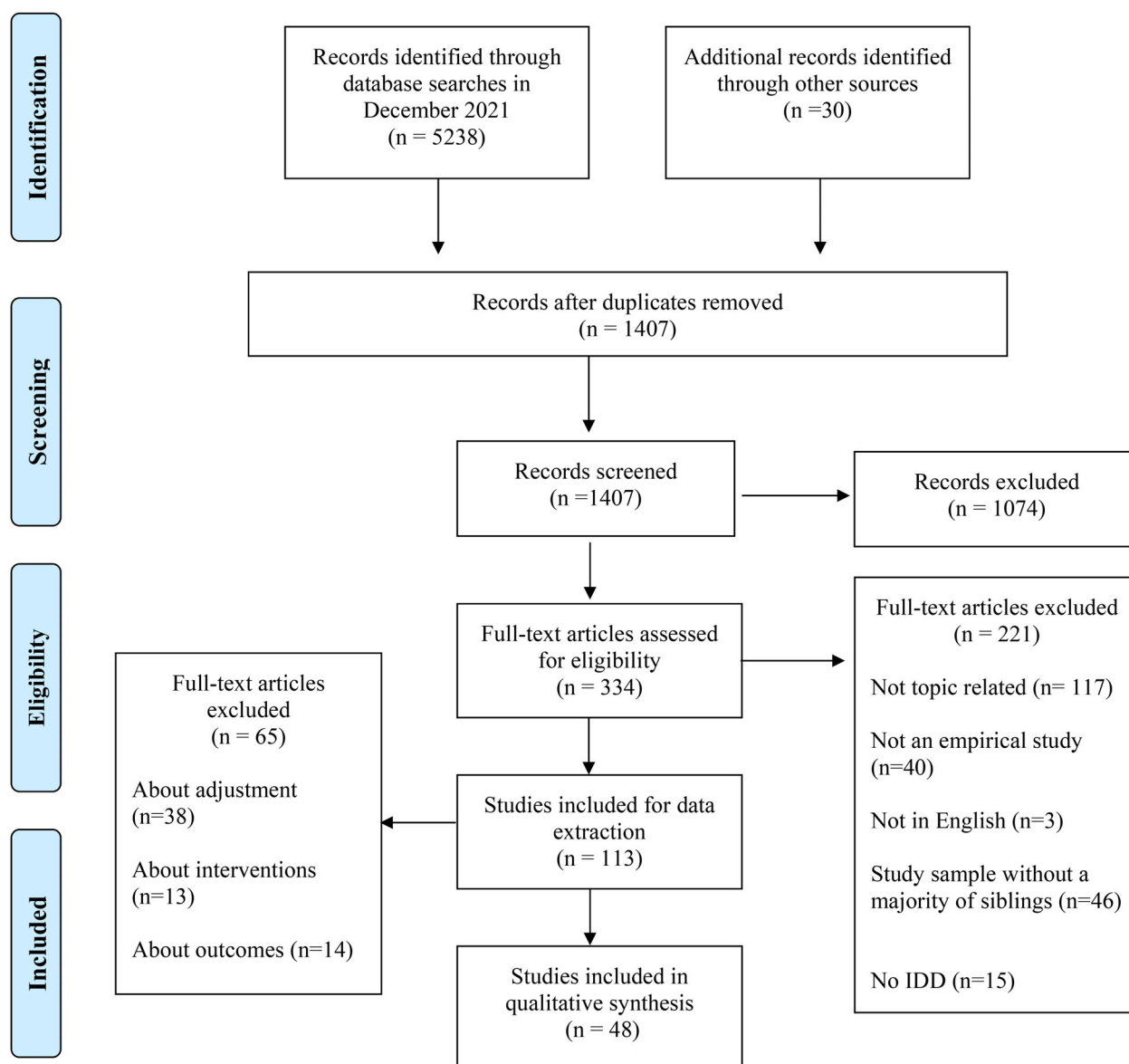


Figure 1. Study flow diagram (PRISMA, Liberati et al. 2009).

Eligibility criteria

Included studies met the following criteria: (a) published between 2003 (the approximate date when the concept of “family quality of life” appeared for the first time, even when aspects of living for people with ID was referred to in early years [see Park et al. 2003]) and 2021; (b) focus on siblings’ quality of life, siblings’ well-being, siblings’ relationships, siblings’ adjustment, and/or siblings’ outcomes; (c) empirical studies; (d) English language; (e) data coming from siblings themselves; and (f) members with at least one sibling with IDD.

As noted in Saxena and Adamsons (2013) siblings of people with IDD ‘has come from research that is largely cross-sectional and atheoretical’ (p.300); leading to a general situation of diverse and unconnected information about siblings. The present systematic review followed the specific domains that are used in the quality of life approach when collecting data and analysing the selected articles. Considering the definition by Zuna et al. (2010) given

above, FQoL employs a variety of domains, but only some of them were applied to siblings’ perceptions. Domains from the International Family Quality of Life Project (Brown et al. 2006) and from the Beach Center Family Quality of Life Scale (Hoffman et al. 2006) were followed. Specifically, domains such as Family interaction/Family relationships, Emotional well-being, Support from other people/from disability related services, Influence of values, Leisure and recreation and Community interaction were used. However, before considerations can be made of wider characteristics of FQoL, it is necessary to know what do the individuals feel about being siblings of a person with an IDD. Therefore, information about siblings’ well-being and siblings’ emotional experiences were taken as a starting point in selecting the articles for this review.

Selection of the studies

Once all the records were retrieved and duplicates removed, titles and abstracts were screened. In order to

ensure reliability, two reviewers used the eligibility criteria to conduct a full-text reading of the selected articles ($N = 334$) and agreed to explain their rejections during several discussions until they reached a consensus (initial agreement, 86.43%).

Data extraction and coding procedures

Relevant articles were codified in a data extraction table that was developed based on the research questions of the review. Articles were coded based on the author, title, year of publication, sample characteristics, theoretical framework, methodology, key findings, outcomes about siblings' quality of life, information reported by parents about siblings, country, and cultural values. To perform a more accurate codifying and categorizing process, Atlas-ti Scientific Software Development GmbH (v8.4.4) a computer-assisted software to analyse large amount of qualitative data was used.

After this process was completed, the authors redefined the inclusion criteria to include only those articles reporting information related to siblings' quality of life, their experiences and perceptions of being siblings. Articles focused on outcomes or interventions ($n = 65$) were finally excluded because their approach was either too narrow for the purposes of this review or presupposed a clear negative experience on siblings (see Figure 1). Two reviewers checked the extracted data and disagreements were discussed among all authors.

Data analysis and quality assessment

All but one of the selected articles had a qualitative research design. Before initiating the data analysis process, the quality of the selected articles was evaluated using the Critical Appraisal Skills Programme (2013), one of the most popular tools to evaluate the quality of qualitative articles (Long et al. 2020). The questions of this tool were applied to each paper (questions considered most important: "Was there a clear statement of the aims of the research?"; "Was the research design appropriate to address the aims of the research?"). Each question was scored zero, one or two depending on the accuracy of the information presented in the article, with an overall score of 20. The 47 articles achieved a score of 17 or above implying a high-quality article³. The quality of the quantitative article was successfully evaluated through AXIS tool (Downes, et al. 2016).

Articles were analysed using a qualitative content analysis. Due to the novelty of the topic, findings were coded line-by-line in an inductive process. Afterwards, data was categorized into descriptive themes such as siblings' relationships, siblings' needs and supports. These themes were then matched with the above domains of Family Quality of Life. Resultant themes and their codes were critically reviewed by the authors during reflexive meetings and discrepancies during the process were discussed until a consensus was reached.

Finally, these themes were used to report the findings, after being grouped into two broad categories derived from the main questions of this review: 1) Siblings' perceptions of their quality of life; 2) Issues of concern and challenges for siblings regarding quality of life.

Results

This section presents the results of the 48 reviewed articles listed in Table 1. A total of 902 individuals participated in the selected articles. Of these, 540 were female, 276 were male, and there was no gender information for the remaining 86 individuals. The participants' age ranged from 4 to over 80 years old. Due to the presence of the discussed topics throughout the siblings' life, findings are generally reported without distinction of siblings' age. However, when specific age groups were reporting something, this was clearly stated. Articles included siblings of people with mild, severe and profound intellectual disabilities (ID), developmental disabilities (DD), learning disabilities, autism spectrum disorder (ASD), cerebral palsy (CP), Down syndrome (DS), 22q11.2 deletion syndrome, rare disorders and a combination of disabilities such as ID and ASD.

Regarding the theoretical frameworks, 11 of the 48 analysed studies named the framework used to conduct the research. The FQoL approach was one of the most referred frameworks (5; 9; 27; 30; 33; 34). Another theoretical framework was the social constructionist research paradigm (4; 31) and Thomas' (Thomas, 1999) social relational model of disability (45). McGraw and Walker (2007) used other theoretical approaches: critical feminism, symbolic interactionism, phenomenology, cultural sociology, and poststructuralism. From the adapted Lifeworld framework by Galvin and Todres (2013), Pavlopoulou and Dimitriou (2019) has followed an experience-sensitive approach constituted by 8 dimensions to understand the siblings' experiences. Finally, Pompeo (2009) used social ecology/ecological psychology, family systems theory, labelling theory, and the social model of disability.

Siblings' perceptions of their quality of life

Family interaction

Findings suggested that family interaction, like communication and daily contact, can shape siblings quality of life in both positive and negative ways. Four articles (1; 17; 35; 41) reported that siblings feel close to their family through bonds of love while holding negative feelings if family dynamics have placed their siblings with IDD at the centre of the family life. Three articles (1; 2; 27) highlighted that siblings' relationships with their brothers or sisters may be influenced by difficulties related to the disability, but these difficulties must be placed within the specific context and family dynamics. For example, as noted in one article (9) certain routines

Table 1. Characteristics of included studies.

Author(s); Year; Country	Focused on	Interviews	Method		Sample		Type of IDD
			Other data- collecting instruments	Size	Age		
1. Atkin and Tozer, 2014. UK	Siblings' perspectives on having a brother or sister with autism; how their relationships were negotiated and given meaning across the course of life	X		n = 21	25-67	ASD + Learning Disability ASD	
2. Bachraz and Grace, 2009. Australia	Sibling' relationships when one sibling has ASD	X	Photographs in interviews Naturalistic observations	n = 3	4-6		
3. Benderix and Sivberg, 2007. Sweden	Experiences of siblings with a brother or sister with autism and mental retardation	X		n = 14	5-29	ASD + Mental Retardation ID	
4. Bigby, Webber and Bowers, 2015. Australia	Siblings roles in the lives of older people with intellectual disability and those who live in group homes; the relationships between residents' siblings and group home staff	X		n = 14	50-70		
5. Boelsma, Caubo-Damen, Schippers, Dane and Abma, 2017. The Netherlands	The dynamics between the family members and their Quality of Life and Family Quality of Life	X		n = 1	23	ID and autistic-related behaviour ID	
6. Cameron, 2010. USA	The author's own path from sibling to sibling-parent		Autoethnography	n = 1	Adults		
7. Canary, 2008. USA	How family members construct notions of ability and disability and how interactions with individuals outside the family influence those family members' constructions	X	Observations; Member validation of transcripts	n = 12	Children	Invisible disabilities	
8. Connell, Halloran and Doody, 2016. Ireland	Sister's experience of growing up with a brother with ASD; professionals understanding of the sister's perspective		Ethnography	n = 1	Adults	ASD	
9. Correia and Seabra-Santos, 2021. Portugal	Siblings' perspectives about the experience of having a sibling with ID and about their family quality of life (FQoL).	X		n = 6	17-56	ID	
10. Corsano, Musetti, Guidotti and Capelli, 2017. Italy	Experiences of growing up with a brother with an ASD	X		n = 14	12-20	ASD	
11. Coyle, Kramer and Mutchler, 2014. USA	The transition in care from parents to siblings, from the perspective of a sibling of an individual aging with IDD	X		n = 15	>40	DS, IDD, ASD and CP ASD	
12. Cridland et al. 2016. Australia	Experiences, roles, and responsibilities of sisters of a brother with an ASD, at school and home from the perspective of different family members	X		n = 3	16-17	ASD	
13. Dansby, Turns, Whiting and Grane, 2018. USA	Experiences of siblings growing up alongside a brother or sister with autism		Posts from online blogs	n = 65	17-31	ASD	
14. Davys, Mitchell and Haigh, 2016. UK	Perceptions of siblings of adults with ID regarding future wishes and family expectation of future support	X	Survey	n = 15	30-64	ID	
15. Diener, Anderson, Wright and Dunn, 2015. USA	Sibling' relationships of students enrolled in a technology education program designed for youth with an ASD	X		n = 7	7-14	ASD	
16. Flaton 2006. USA	Life experiences of a woman growing up with a brother with Down Syndrome	X		n = 1	39	DS	
17. Goodwin, Alam and Campbell, 2017. UK/Australia	The interpretations of youth and adults who have a sibling with 22q11.2 Deletion Syndrome from a phenomenological epistemological position	X		n = 5	16-42	22q11.2 deletion syndrome ASD	
18. Goriy, Fielding and Falkmer, 2017. Australia	How adolescent siblings of children with Autism Spectrum Conditions view their life	X		n = 11	12-17	ASD	
19. Graff et al. 2012. USA	Experiences of adolescent siblings of a child with DS plus health problems	X		n = 23	12-19	DS+ Multiple	

(Continued)

Author(s); Year; Country	Focused on	Method		Sample			Type of IDD
		Interviews	Other data- collecting instruments	Size	Age		
20. Hall and Rossetti, 2018. USA	Roles of siblings regarding their brothers or sisters with severe intellectual and developmental disabilities		Survey with four open-ended questions	n = 79	19-72	Health Problems IDD	
21. Hames, 2008. UK	How and when siblings understand that they have a brother or sister with a learning disability	X		n = 12	12-14	Learning Disability Rare disorders	
22. Haukeland, Fjermestad, Mossige and Vatne, 2015. Norway	Emotional experiences of siblings of children with rare disorders		Support Groups	n = 58	7-17		
23. Hwang and Charney, 2010a. South Korea	Experiences of children living with an autistic sibling		Visual ethnographic methods/ video elicitation	n = 9	7-15	ASD	
24. Hwang and Charney, 2010b. South Korea/UK	The role of culture in understanding autism		Visual ethnographic	n = 9	7-15	ASD	
25. Jacobs and MacMahon, 2017. Scotland	Experiences of young adults with a sibling with an ID placed in a residential school	X		n = 6	16-22	Learning Disability IDD	
26. Kao, Romero-Bosch, Plante and Lobato, 2012. USA	Experiences of Latino siblings of children with developmental disabilities	X		n = 17	8-14		
27. Kyrkou, 2018. Australia	Practical aspects of the sibling relationship through the major developmental stages of early childhood, school years, adolescence, and the shift into adulthood		Autoethnography	n = 1	Adults	Unknown condition	
28. Lemoine and Schneider, 2021. France	Adult siblings perceptions of their childhood relationships with brothers or sisters with DS		Online survey	N = 120	18-80	DS	
29. Luijkx, van der Putten and Vaskamp, 2016. The Netherlands	Experiences of having a sibling with profound intellectual and multiple disabilities		Photo elicitation interviews	n = 18	6-13	PIMD	
30. Mascha and Boucher, 2006. UK	Experiences and feelings of siblings with a brother or sister with autism	X		n = 14	11-18	ASD	
31. McGraw and Walker, 2007. USA	How gender and developmental disability discourses shape nondisabled women's understandings of themselves and their siblings with disabilities	X		n = 10	21-82	DD	
32. Mouzourou, Santos and Gaffney, 2011. USA/Cyprus	Family experiences with a child with autism	X	Observations of their daily routines	n = 3	6,10,12	ASD	
33. Moyson and Roeyers, 2011. Belgium	Siblings of children with ASD' descriptions and definitions of their quality of life	X		n = 17	6-14	ASD	
34. Moyson and Roeyers, 2012. Belgium	Siblings definition of their quality of life as a siblings	X		n = 50	6-14	ID	
35. Noonan et al. 2018. Ireland	Experiences of siblings of adults with an ASD and ID	X	Focus groups	n = 8 n = 22	18-37 8-25	ASD + ID ID	
36. Paul et al. 2021. USA	Experiences of siblings of people with intellectual disabilities in Latin America, Africa, and Asia-Pacific						
37. Pavlopoulou and Dimitriou, 2019. UK	Unexplored factors in the life of adolescents' sisters with a brother or sister with an ASD	X		n = 9	12-14	ASD + ID	
38. Petalas, Hastings, Nash, Dowey and Reilly, 2009. UK	Perceptions and experiences of siblings with a brother with an ASD	X		n = 8	9-12	ASD	
39. Petalas, Hastings, Nash, Reilly and Dowey, 2012. UK	How adolescent siblings with a brother with an ASD make sense of their unique circumstances and experiences	X		n = 12	14-17	ASD	
40. Pompeo, 2009. USA		X		n = 5	22-25	Disability	

(Continued)

Author(s); Year; Country	Focused on	Method		Sample		
		Interviews	Other data- collecting instruments	Size	Age	Type of IDD
41. Rampton et al. 2007. USA	Sisters' experiences within educational and public domains; how such experiences have shaped their personalities and career choices What is important for siblings of children with Down Syndrome		Photo elicitation interviews	n = 16	7-15	DS
42. Rawson, 2010. UK	Concerns young adult siblings have for the future; what support they need to develop and improve support for their siblings	X		n = 13	17-23	ASD + Learning Disability Severe Disabilities ASD
43. Rossetti and Hall, 2015. USA	Siblings' relationship perceptions with brothers or sisters with severe disabilities		Survey with four open-ended questions	n = 79	19-72	Disability
44. Sage and Jegatheesan, 2010. USA	Siblings' perceptions of their brothers with autism and their relationships with them	X	Video recorded observations of siblings playing	n = 2	7	ASD + Learning Disability Disability ASD + Learning Disability
45. Stalker and Connors, 2004. Scotland/ UK	Siblings' understandings and experiences of disability	X		n = 24	6-19	Disability
46. Tozer and Atkin, 2015. UK	Expectations of social care among siblings	X		n = 21	25-67	ASD + Learning Disability Disability ASD + Learning Disability
47. Tozer, Atkin and Wenham, 2013. UK	Siblings' relationships where one of them have autism and severe learning disability	X		n = 21	25-67	ASD + Learning Disability Disability ASD + Learning Disability
48. Vella Gera et al. 2020. Malta	The experiences of young siblings of children with disability in Malta	X	Focus group	n = 7	8-12	CP, DS and ASD

ASD, autism spectrum disorder; IDD, intellectual and developmental disabilities; ID, intellectual disabilities; DS, down syndrome; CP, cerebral palsy.

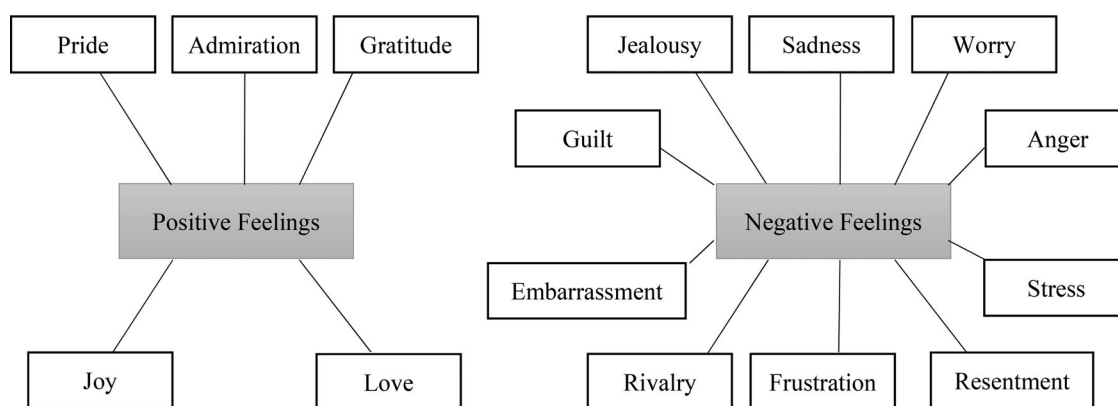


Figure 2. Positive and negative feelings experienced by siblings towards their brothers or sisters with IDD.

established by parents, like insisting their children play together, may have a negative effect on siblings' well-being if they are required to watch over their brothers or sisters when they do not wish to.

Five articles (19; 22; 25; 31; 35) reported that siblings value how family dynamics are influenced by disability by stimulating a family sense of uniqueness and togetherness. In contrast, 10 articles (12; 14; 18; 23; 31; 32; 38; 39; 46; 47) stated that disability can affect family life when distressful moments, like public outbursts of the sibling with IDD, occurred. Four articles (17; 33; 34; 45) indicated that child and adolescent siblings might prefer not to share their worries with their parents to avoid putting more pressure on them and three articles (9; 12; 30) referred how siblings appreciate opportunities to be alone with their parents. Three articles (2; 17; 27) reported that siblings understand different parental treatment towards siblings with IDD, such as giving them more attention, but 8 articles (18; 22; 28; 30; 31; 38; 40; 48) affirmed that siblings could be in conflict between accepting that difference while feeling anger or lacking parental attention.

Siblings with and without IDD' relationships

Seven articles (20; 28; 36; 43; 46; 47; 48) indicated that siblings with and without IDD share a unique and long-lasting relationship. In another five (2; 8; 15; 36; 41) siblings view these relationships as a mutual space to grow and share activities, and one article (48) reported that it goes beyond the brother or sister' disability. However, in two articles (7; 13) siblings have expressed negative sentiments toward their brothers or sisters with disability and described moments of conflict, dispute, or burden due to caregiving duties. The ambivalence of the siblings' relationship is noted in almost half of the articles (1; 6; 7; 10; 12; 13; 15; 17; 18; 19; 22; 23; 25; 30; 31; 35; 38; 39; 43; 44; 45; 46; 47). Two of them (15; 47) explained it as a common characteristic of siblings' relationships regardless of the presence of disability.

Two articles (25; 46) showed that disability influences siblings' relationships. Communication impairments, disruptive behaviour, or limited reciprocity from brothers or sisters with IDD may affect them, as noted in 14 articles (1; 10; 12; 17; 22; 33; 36; 37; 38; 39; 43; 44; 47; 48). In 10 articles (9; 19; 20; 29; 33; 35; 36; 37; 44; 48) siblings awareness of their brothers or sisters' needs lead them to adapt accordingly communication and activities.

Three articles (39; 45; 48) revealed an empathetic sense from child and adolescent siblings towards their brothers or sisters and four articles (18; 35; 43; 48) reported the use of love, humour and joy to reinforce their relationship. Hall and Rossetti (2018) indicated that, as siblings grow up, their relationship will involve higher levels of caregiving. Three articles (24; 28; 31) have referred to the gendered nature of caregiving and how sisters have had to deal with the social pressure of being a woman added to the familial obligation placed on them as sisters.

Emotional well-being

Figure 2 presents the most referred feelings from siblings related to having a brother or sister with IDD. In two articles (22; 34), the behaviour of siblings with IDD or their recurrent medical issues, were highlighted as a strong influence on child and adolescent siblings' well-being promoting feelings of compassion toward them. One article (9) reported the well-being of brothers and sisters with disability as important for siblings' quality of life.

Nine studies (9; 17; 23; 29; 31; 33; 34; 38; 39) reported that accepting the family situation has positive consequences for siblings. As stated in three articles (17; 33; 36), the pragmatic acceptance of their brothers or sisters with IDD, helps siblings to adjust and even to benefit from the relationship. In two articles (9; 48) siblings reported that parental positive views and acceptance of their child's disability, has influenced the rest of the family to accept it as well, improving their family quality of life. However, as noted in three articles (9; 39, 48),

Table 2. Siblings roles towards brothers or sisters with IDD.

Friendship role
<ul style="list-style-type: none"> • Providing support, experiences and leisure activities. • Being able to understand and comprehend brothers or sisters with IDD and to perform as their translators for other people, including their parents. • Having a protective role. • Friendship relationship constituted by an amount of fun, confidence and trustworthiness.
Caregiving role
<ul style="list-style-type: none"> • More equal and flexible role than their parents. • Starting during childhood in a natural way. • In the adulthood, supporting brothers or sisters with IDD to deal with the decease of parents and relatives. • Siblings' concerns about what will happen to brothers or sisters with IDD if they could not look after them anymore due to their own age-related declining or death. • Transition in the caregiving role from parents to siblings: easier and fairer if parents and professionals value siblings' voices and opinions from the beginning and clear future care plans are established together.
Advocate role
<ul style="list-style-type: none"> • Standing up for brothers or sisters with IDD' interests and rights. • May cover all areas of brothers or sisters with IDD life, including family, school or the larger community. • Being informants and defendants of their siblings with IDD in front of peers, teachers or strangers. • Feelings of incompetence and stress when trying to carry out similar standards of care as their parents while trying to maintain their own family life and obligations.
Legal representative role
<ul style="list-style-type: none"> • Legal guardians of siblings with IDD. • Lack of information about guardianship. • Distress when having to take some important decisions about their siblings.

IDD, intellectual and developmental disabilities.

sometimes this acceptance comes with a desire to change their brothers or sisters' behaviour or condition.

Influence on identity construction

Having a brother or a sister with IDD may influence siblings' personality and subjective decisions. In ten articles (12; 16; 18; 19; 21; 22; 25; 36; 40; 48), siblings realize how their brothers or sisters with IDD have positively shaped their personality and the way they give meaning to life, and two articles (7; 31) showed that relationships among siblings have a preponderant role on identity construction.

In another twelve (10; 14; 16; 17; 19; 28; 30; 33; 34; 36; 37; 48) siblings consider themselves more mature and patient than their peers due to circumstances of their daily life and, in seven articles (16; 17; 22; 29; 35; 40; 48) also more empathetic with others. One study (6) indicated that having a brother or sister with IDD could affect siblings' decisions about having their own children. Six articles (9; 13; 14; 16; 21; 40), also reported some siblings chose professional employment related with care professions on special educational field.

Influence of cultural and religious values

Cultural constructions about disability differ from context to context and have different effects in the siblings' lives. Three articles (25; 32; 40) from a variety of countries, noted that cultural perceptions might lead to feelings of guilt, shame, or isolation by determining the definition of "normalcy" and "exceptionality". These views are also held in other studies (31; 36; 45) and indicated how the religious views on siblings' reflections about disability could lead to the idea that the person with an IDD is someone who has to be healed, represents God's punishment or alternatively is a holy gift to their family, as collected in the study from

Cyprus (32). Religion can also help families overcome tough moments, as reported in one article (9).

In the South Korean studies (23; 24) all members of the family shared a mutual commitment with the family system. Siblings' sacrifices for their brothers or sisters with autism are connected with filial obligation, experimenting pride derived from its fulfilment. Similar values were found in the articles with Latino families in the USA (26), siblings from Latin America, Africa and Asia-Pacific (36) and from Southern European countries (9; 10; 32; 48) where siblings used to have more caregiving responsibilities and reported positive and negative feelings regarding it.

Roles and responsibilities

Table 2 (structured following Hall and Rossetti 2018) summarizes the roles and responsibilities carried out by siblings. In addition, three articles (23; 26; 31) referred how the impact on the performance of roles is the way siblings are willing to be a good sibling; Coyle *et al.* (2014) stated that roles change according to age.

Community interaction

As individuals, siblings have bonds with their communities and are positively and negatively affected by them. Seven articles (9; 33; 35; 36; 37; 40; 48) reported that siblings might face challenges or difficulties because of social views regarding disability. According with Tozer *et al.* (2013) these experiences create feelings of segregation on siblings and their families while, at the same time, improve their self-confidence. In at least 13 articles (18; 24; 25; 27; 29; 32; 34; 36; 37; 38; 39; 45; 47) siblings referred to misunderstandings and negative public judgment together with the importance of being treated normally and of educating society about disability. In six articles (24; 30; 31; 33; 35; 39) behavioural

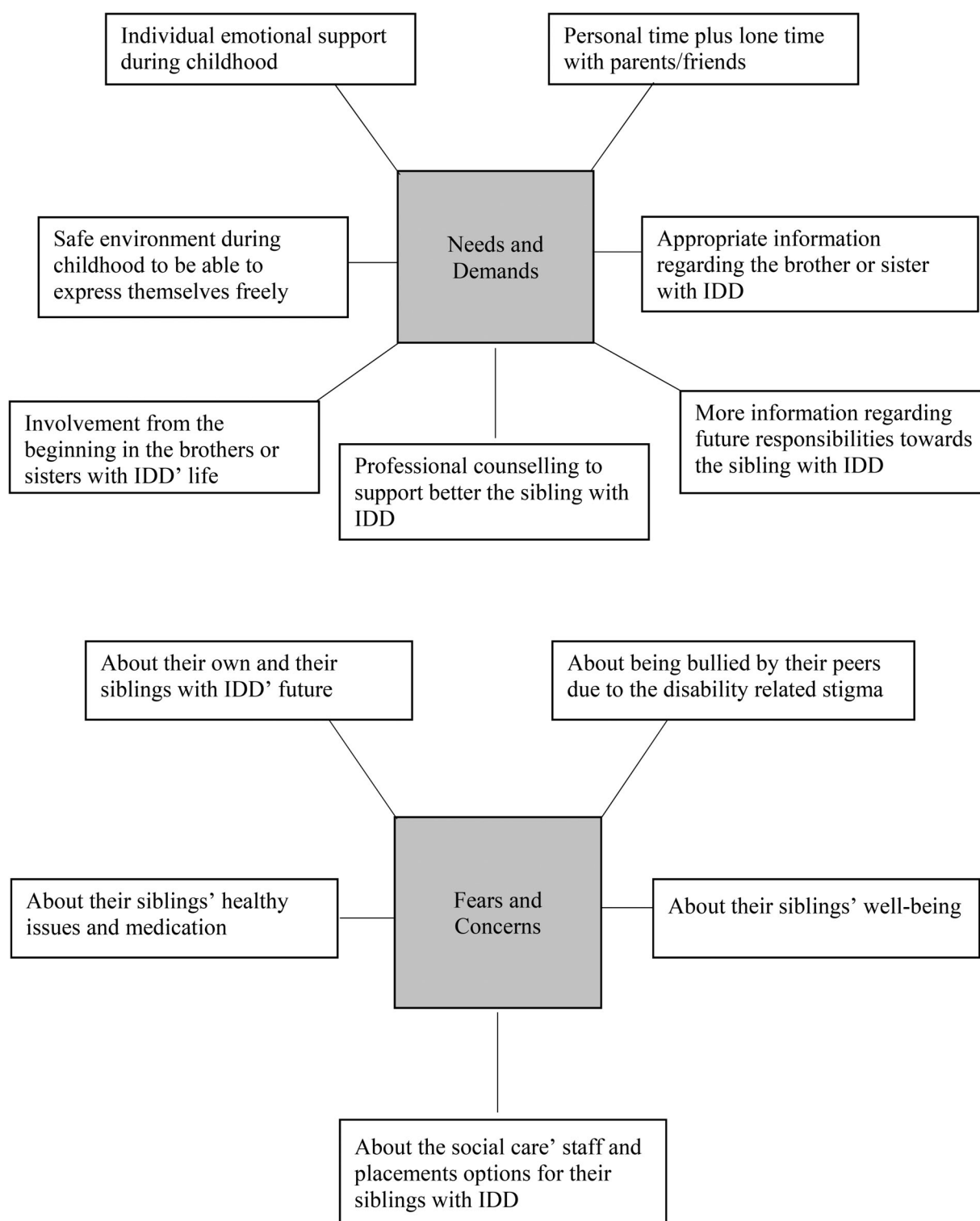


Figure 3. Siblings needs and concerns regarding having a brother or a sister with IDD.

problems and the invisibility of autism are stated by siblings of all ages as some of the most difficult situations when dealing with the outside world.

Two articles (24; 39) noted that adolescent siblings could feel shame and loneliness due to stigma. Another article (36) referred to the stigma within the family, meaning that families are not protected from negative assumptions regarding disability. However, four articles (16; 24; 25; 31) indicated that siblings succeed in hav-

ing a life of quality and in building and maintaining a lifelong relationship with their siblings.

Issues of concern and challenges for siblings regarding quality of life

Siblings' needs and desires

During their lifespan, siblings have a variety of desires, needs and concerns that were reported throughout the reviewed studies. One article (36) mentioned siblings

wanted to be a good model for their brothers or sisters. In six articles (10; 18; 21; 33; 34; 48) children and adolescent siblings expressed willingness to share their experiences with other siblings of people with IDD to feel understood and to learn ways to behave and relate better with their brothers or sisters with IDD. Six studies (9; 16; 26; 38; 45; 46) noted how siblings wished to enjoy neat, clear, and straight communication with their parents to obtain practical information about their siblings with IDD, discuss delicate issues, and consider how to deal with eventual circumstances.

In nine articles (8; 9; 31; 34; 38; 39; 43; 47; 48) some siblings were eager to have a 'normal' family with brothers and sisters displaying ordinary communication and behaviour. Figure 3 provides the siblings' most mentioned needs, demands, fears and concerns.

Disability related-support

Siblings expressed different experiences regarding formal and informal supports due to having a brother or a sister with IDD. In one article (36), siblings wished more and better services for their brothers or sisters. Two articles (35; 46) indicated that adult siblings felt ignored or excluded by parents and practitioners. In another two studies (42; 47) young and adult siblings noted that they were not always sure to what extent they could be involved in their siblings' lives or about how to approach the different types of available support. In contrast, seven articles (3; 8; 25; 31; 35; 38; 46) found that siblings of all ages valued respite care facilities, residential placements for brothers and sisters in adulthood, and maintaining a positive and trusting relationship with staff and service providers.

Twelve articles (9; 12; 14; 16; 17; 18; 20; 28; 31; 37; 47; 48) reported that siblings appreciate having support from other siblings, friends, parents, extended family and the larger community. Six articles (8; 9; 11; 33; 34; 38) mentioned as support leisure time without their brothers or sisters with IDD, sharing experiences and responsibilities.

Discussion

This review aimed to explore siblings' perceptions of quality of life collected in the literature. Results indicated that siblings perceptions are personally oriented and influenced by the context. Previous studies have shown that disability permeates different areas of siblings' life. Despite this, the present review revealed that the reality of disability could not by itself explain the characteristics of siblings' quality of life perceptions. Their relationship appears more extensive, variable and complex. It is important to note that the influence of established family dynamics and the social responses perceived by siblings affected their willingness to fulfil certain roles. This appears to be a complex determinant affecting siblings' perceptions of quality of life.

We have seen that during their development, siblings reported different issues affecting their perceptions of quality of life due to having a brother or a sister with IDD. During childhood and adolescence, siblings empathic feelings towards their brothers or sisters might also be linked to feelings of loneliness and shame. However, siblings used to hesitate about sharing their concerns with their parents, due to parental reactions towards disability, such as the establishment of specific dynamics and interactions in the nuclear family. Further, parental expectations towards the responsibilities siblings should take, may disturb the well-being of the siblings if not clearly explained and understood by them. This resonates with data obtained in Rillotta *et al.* (2012) where main caregivers noted that if siblings perceived themselves as being put in a second position in relation to the brother or sister with IDD, negative reactions can give rise to misbehaviour. At the same time, siblings referred to being positively influenced by their brothers or sisters with IDD resulting in greater maturity and socially sensitive and abled than their peers. As noted on the research by (Findler and Vardi, 2009) understanding what is going on with their brothers or sisters and growing alongside a person with a disability, may lead to improvement in siblings' psychological growth.

The demands on the adult sibling regarding their quality of life seems to be related to being recognized in their efforts to support their brothers or sisters with IDD. Findings showed that siblings hold multiple roles and responsibilities towards their brothers or sisters with IDD, most of them appeared to be in a positive way, but several did indicate their contribution is not valued enough by parents and services. This finding was also reported in Arnold *et al.* (2012) where siblings requested further inclusion and active participation in disability related services to improve their support for their siblings with a disability. The lack of recognition could cause supportive siblings feelings of disappointment and sorrow and affect negatively their own perceptions of well-being and quality of life. However, it appears that these reactions did not persuade them to end their involvement or their relationship with brothers or sisters with IDD; on the contrary, our findings indicated that siblings decide fiercely to keep their engagement and bond with brothers and sisters with IDD frequently involving commitment, responsibility and love towards them.

The relationships siblings have with the larger community and with their cultural context, seem to affect their perceptions of quality of life due to the influences of embedded values and social myths about disability. These results are in accordance with the unified theory of family quality of life by Zuna *et al.* (2009) that highlights the continuous interaction between individual, family and social levels and its effects on family quality

of life. Indeed, the family quality of life approach has an ecological and systemic foundation (see Turnbull *et al.* 2004) and considers the influence that the interaction of these three levels have on families in order to understand their experiences and needs.

On account of the external influences on siblings' quality of life (e.g. financial wealth, availability of supports, good relationship with service providers) it is interesting to note the role that disability-related stigma can play. Stigma is constituted by culturally established ideas about what disability is or what having a relative with an IDD could be, constraining siblings' sense of normalcy (Hwang and Charnley, 2010b). These results are consistent with the work of Brown *et al.* (2019) who have discussed how new eugenics practices can negatively pervade the perceptions of quality of life of people with IDD and their families, due to a reliance on "the idea that a life with disability, especially one with severe disability, is troublesome and lacking in quality for the individual with disability and supporting family members" (p.122). Nevertheless, many siblings are able to have a meaningful life and to develop their own sense of normalcy intertwined with feelings of exceptionality.

Limitations of the review

Whilst this review has contributed to knowledge on siblings' quality of life from childhood to adulthood and about their needs and desires from their own voice, there are three factors that can limit the scope of our findings. The first one is the general lack of a clear theoretical framework in the majority of the reviewed articles. The second one is that the number of female participants in the selected articles was found to be significantly higher ($n = 540$) than the number of male participants ($n = 276$). Although this seems to be the general tendency in studies in the field, this may be a bias regarding gender, as reported in Doody *et al.* (2010). A third limitation is that the data gathered is predominantly from Western and English-speaking countries with a Judeo-Christian culture and tradition. Further, participants come predominantly from a middle and high socioeconomic status with a high educational level. Some authors referred to this homogeneity as a limitation of their studies (1; 11; 19; 20; 33; 34; 35; 37; 41; 43; 47) and recommended researching with individuals from different backgrounds, educational levels and socioeconomic status, as pointed out in the review by Heller and Arnold (2010). Community-based participatory research (CBPR) (see Pavlopoulou and Dimitriou, 2020) may result in positive outcomes by involving siblings from the first stages of the research to influence policies and services directed to enhance their quality of life.

Conclusions and directions for future research

This review contributes to a broader understanding of siblings' perceptions of quality of life when they have a brother or a sister with IDD. The family quality of life approach appears a useful approach to gathering an overall image of siblings' quality of life. The findings reported significant information regarding the varied and often positive aspects of the personal experiences of siblings, providing a global view of their quality of life' perceptions. Their needs, desires and concerns were also reported, like the importance of promoting siblings' involvement from the beginning of the lives of their brothers or sisters with IDD, including empowering them with disability related information and emotional resources from childhood into adulthood. As such this is relevant information for practitioners and policy makers in the disability field. Further research is required to better detect and understand siblings' needs in order to develop early and accurate interventions. Therefore, research with siblings from other cultural frameworks and socioeconomic status should be undertaken.

Further research may refer to the importance of educating local communities and to explore the role of siblings educating them about what is it like to be a sibling or what their needs are (Pavlopoulou and Dimitriou, 2020). Additionally, it is important to conduct research with explicit theoretical frameworks together with designs that take into account the multiple components of a system that might be influencing siblings' well-being (Correia and Seabra-Santos 2021, Kovshoff *et al.* 2017). More research is needed about the influence that having a brother or sister with IDD may have on siblings schooling experiences and later further education. Balanced narratives that recognize the nature of disability are necessary in building positive sibling relationships (Meltzer, 2018). Finally, it would be interesting to explore the experiences of siblings in related contexts, like siblings of individuals with chronic conditions or children living with parents with an intellectual disability.

Notes

1. *Mental Retardation* was included as a keyword because it was widely used until recent years.
2. *Learning Disabilities* was included because it is commonly used in the United Kingdom and other Anglo-Saxons countries to refer to ID.
3. Table with the reported information will be provided by requesting the first author (olgamcl@blanquerna.url.edu).

Conflict of interest

No conflict of interest has been declared.

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References

- Arnold, C. K., Heller, T. and Kramer, J. 2012. Support needs of siblings of people with developmental disabilities. *Intellectual and Developmental Disabilities*, 50, 373–382.
- Atlas.ti Scientific Software Development GmbH. 2002–2019. *ATLAS.ti*. Berlin: Atlas.ti Scientific Software Development GmbH.
- *Atkin, K. and Tozer, R. 2014. Personalization, family relationships and autism: Conceptualizing the role of adult siblings. *Journal of Social Work*, 14, 225–242.
- *Bachraz, V. and Grace, R. 2009. Creating a different kind of normal: parent and child perspectives on sibling relationships when one child in the family has autism spectrum disorder. *Contemporary Issues in Early Childhood*, 10, 317–330.
- *Benderix, Y. and Sivberg, B. 2007. Siblings' experiences of having a brother or sister with autism and mental retardation: A case study of 14 siblings from five families. *Journal of Pediatric Nursing*, 22, 410–418.
- *Bigby, C., Webber, R. and Bowers, B. 2015. Sibling roles in the lives of older group home residents with intellectual disability: Working with staff to safeguard wellbeing. *Australian Social Work*, 68, 453–468.
- Blacher, J., Neece, C. and Paczkowski, E. 2005. Families and intellectual disability. *Current Opinion in Psychiatry*, 18, 507–513.
- *Boelsma, F., Caubo-Damen, I., Schippers, A., Dane, M. and Abma, T. A. 2017. Rethinking FQoL: The dynamic interplay between individual and family quality of life. *Journal of Policy and Practice in Intellectual Disabilities*, 14, 31–38.
- Brown, I., Brown, R. I., Baum, N. T., Isaacs, B. J., Myerscough, T., Neikrug, S., Roth, D., Shearer, J. and Wang, M. 2006. *Family quality of life survey: Main caregivers of people with intellectual or developmental disabilities*. Toronto: Surrey Place Centre.
- Brown, I., Brown, R. I. and Schippers, A. 2019. A quality of life perspective on the new eugenics. *Journal of Policy and Practice in Intellectual Disabilities*, 16, 121–126.
- *Cameron, L. 2010. Maine is still my best medicine: An update on the path from sibling to sibling–parent. *Intellectual and Developmental Disabilities*, 48, 478–479.
- *Canary, H. E. 2008. Negotiating dis/ability in families: Constructions and contradictions. *Journal of Applied Communication Research*, 36, 437–458.
- Chiu, C.Y., Seo, H., Turnbull, A.P. and Summers, J.A. 2017. Confirmatory factor analysis of a family quality of life scale for Taiwanese families of children with intellectual disability/developmental delay. *Intellectual and Developmental Disabilities*, 55, 57–71.
- *Connell, Z. O., Halloran, M. O. and Doody, O. 2016. Living with a brother who has an Autism Spectrum Disorder: A sister's perspective. *British Journal of Learning Disabilities*, 44, 49–55.
- *Correia, R. A. and Seabra-Santos, M. J. 2021. "I would like to have a normal brother but I'm happy with the brother that I have": A pilot study about intellectual disabilities and family quality of life from the perspective of siblings. *Journal of Family Issues*, 1–20. 0192513X211042845.
- *Corsano, P., Musetti, A., Guidotti, L. and Capelli, F. 2017. Typically developing adolescents' experience of growing up with a brother with an autism spectrum disorder. *Journal of Intellectual & Developmental Disability*, 42, 151–161.
- *Coyle, C. E., Kramer, J. and Mutchler, J. E. 2014. Aging together: Sibling carers of adults with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 11, 302–312.
- *Cridland, E. K., Jones, S. C., Stoyles, G., Caputi, P. and Magee, C. A. 2016. Families living with autism spectrum disorder: Roles and responsibilities of adolescent sisters. *Focus on Autism and Other Developmental Disabilities*, 31, 196–207.
- Critical Appraisal Skills Programme. 2013. *Ten questions to help you make sense of qualitative research*. Oxford: Critical Appraisal Skills Programme.
- *Dansby, R. A., Turns, B., Whiting, J. B. and Crane, J. 2018. A phenomenological content analysis of online support seeking by siblings of people with autism. *Journal of Family Psychotherapy*, 29, 181–200.
- *Davys, D., Mitchell, D. and Haigh, C. 2016. Adult siblings consider the future: Emergent themes. *Journal of Applied Research in Intellectual Disabilities : JARID*, 29, 220–230.
- *Diener, M. L., Anderson, L., Wright, C. A. and Dunn, M. L. 2015. Sibling relationships of children with autism spectrum disorder in the context of everyday life and a strength-based program. *Journal of Child and Family Studies*, 24, 1060–1072.
- Doody, M. A., Hastings, R. P., O'Neill, S. and Grey, I. M. 2010. Sibling relationships in adults who have siblings with or without intellectual disabilities. *Research in Developmental Disabilities*, 31, 224–231.
- Downes, M. J., Brennan, M. L., Williams, H. C. and Dean, R. S. 2016. Development of a critical appraisal tool to assess the quality of cross-sectional studies (AXIS). *BMJ Open*, 6, e011458–7.
- Findler, L. and Vardi, A. 2009. Psychological Growth Among Siblings of Children With and Without Intellectual Disabilities. *Intellectual and Developmental Disabilities*, 47, 1–12. doi:10.1352/2009.47:1-12.
- Galvin, K. and Todres, L. 2013. *Caring and well-being: A lifeworld approach*. London: Routledge.
- *Flaton, R. 2006. "Who would I be without Danny?" Phenomenological case study of an adult sibling. *Mental Retardation*, 44, 135–144.
- *Goodwin, J. A., Alam, S. and Campbell, L. E. 2017. 'At the end of the day, it is more important that he stays happy': An interpretative phenomenological analysis of people who have a sibling with 22q11.2 deletion syndrome. *Journal of Intellectual Disability Research : JIDR*, 61, 888–898.
- *Gorjy, R. S., Fielding, A. and Falkmer, M. 2017. "Its better than it used to be": Perspectives of adolescent siblings of children with an autism spectrum condition. *Child & Family Social Work*, 22, 1488–1496.
- *Graff, C., Mandelco, B., Dyches, T. T., Coverston, C. R., Roper, S. O. and Freeborn, D. 2012. Perspectives of adolescent siblings of children with down syndrome who have multiple health problems. *Journal of Family Nursing*, 18, 175–199.
- *Hall, S. A. and Rossetti, Z. 2018. The roles of adult siblings in the lives of people with severe intellectual and developmental disabilities. *Journal of Applied Research in Intellectual Disabilities : JARID*, 31, 423–434.
- *Hames, A. 2008. Siblings' understanding of learning disability: A longitudinal study. *Journal of Applied Research in Intellectual Disabilities*, 21, 491–501.
- *Haukeland, Y. B., Fjermestad, K. W., Mossige, S. and Vatne, T. M. 2015. Emotional experiences among siblings of children with rare disorders. *Journal of Pediatric Psychology*, 40, 712–720.
- Heller, T. and Arnold, C. K. 2010. Siblings of adults with developmental disabilities: Psychosocial outcomes, relationships, and future planning. *Journal of Policy and Practice in Intellectual Disabilities*, 7, 16–25.
- Heller, T. and Kramer, J. 2009. Involvement of adult siblings of persons with developmental disabilities in future planning. *Intellectual and Developmental Disabilities*, 47, 208–219.
- Hoffman, L., Marquis, J., Poston, D., Summers, J. A. and Turnbull, A. 2006. Assessing family outcomes: psychometric evaluation of the beach center family quality of life scale. *Journal of Marriage and Family*, 68, 1069–1083.
- *Hwang, S. K. and Charnley, H. 2010a. Honourable sacrifice: A visual ethnography of the family lives of Korean children with autistic siblings. *Children & Society*, 24, 437–448.
- *Hwang, S. K. and Charnley, H. 2010b. Making the familiar strange and making the strange familiar: Understanding Korean children's experiences of living with an autistic sibling. *Disability & Society*, 25, 579–592.
- *Jacobs, P. and MacMahon, K. 2017. It's different, but it's the same': perspectives of young adults with siblings with intellectual

- disabilities in residential care. *British Journal of Learning Disabilities*, 45, 12–20.
- *Kao, B., Romero-Bosch, L., Plante, W. and Lobato, D. 2012. The experiences of Latino siblings of children with developmental disabilities. *Child: Care, Health and Development*, 38, 545–552.
- Kovshoff, H., Cebula, K., Tsai, H.-W J. and Hastings, R. P. 2017. Siblings of children with autism: The siblings embedded systems framework. *Current Developmental Disorders Reports*, 4, 37–45.
- *Kyrkou, N. 2018. Family quality of life and nurturing the sibling relationship. *International Journal of Child, Youth and Family Studies*, 9, 75–87.
- *Lemoine, L. and Schneider, B. 2021. Growing up with a brother or sister with Down syndrome: Adult siblings' perceptions of their childhood relationships. *Journal of Intellectual & Developmental Disability*, 1–14.
- Liberati, A., Altman, D. G., Tetzlaff, J., Mulrow, C., Gøtzsche, P. C., Ioannidis, J. P. A., Clarke, M., Devereaux, P. J., Kleijnen, J. and Moher, D. 2009. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health-care interventions: Explanation and elaboration. *PLoS Medicine*, 6, e1000100–28.
- Long, H. A., French, D. P. and Brooks, J. M. 2020. Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis. *Research Methods in Medicine & Health Sciences*, 1, 31–42.
- *Luijckx, J., van der Putten, A. A. J. and Vlaskamp, C. 2016. "I love my sister, but sometimes I don't": A qualitative study into the experiences of siblings of a child with profound intellectual and multiple disabilities. *Journal of Intellectual & Developmental Disability*, 41, 279–288.
- *Mascha, K. and Boucher, J. 2006. Preliminary Investigation of a Qualitative Method of Examining Siblings Experiences of Living with a Child with ASD. *The British Journal of Developmental Disabilities*, 52, 19–28.
- *McGraw, L. A. and Walker, A. J. 2007. Meanings of sisterhood and developmental disability. *Journal of Family Issues*, 28, 474–500.
- Meltzer, A. 2018. Embodiment and enacting disability as siblings: Experiencing disability in relationships between young adult siblings with and without disabilities. *Disability & Society*, 33, 1212–1233.
- *Mouzourou, C., Santos, R. M. and Gaffney, J. S. 2011. At home with disability: One family's three generations narrate autism. *International Journal of Qualitative Studies in Education*, 24, 693–715.
- *Moyson, T. and Roeyers, H. 2011. The quality of life of siblings of children with autism spectrum disorder. *Autism Spectrum Disorder. Exceptional Children*, 78, 41–55.
- *Moyson, T. and Roeyers, H. 2012. The overall quality of my life as a sibling is all right, but of course, it could always be better': Quality of life of siblings of children with intellectual disability: The siblings' perspectives. *Journal of Intellectual Disability Research : JIDR*, 56, 87–101.
- *Noonan, H., Donoghue, I. O. and Wilson, C. 2018. Engaging with and navigating limbo: Lived experiences of siblings of adults with autism spectrum disorders. *Journal of Applied Research in Intellectual Disabilities : JARID*, 31, 1144–1153.
- Orsmond, G. I. and Seltzer, M. M. 2007. Siblings of individuals with autism spectrum disorders across the life course. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 313–320.
- Park, J., Hoffman, L., Marquis, J., Turnbull, A. P., Poston, D., Mannan, H., Wang, M. and Nelson, L. L. 2003. Toward assessing family outcomes of service delivery: Validation of a family quality of life survey. *Journal of Intellectual Disability Research : JIDR*, 47, 367–384.
- *Paul, A. M., Hussey, M. M., Woodman, A. C., Smith, A. L. and Shriver, T. P. 2021. Experiences of siblings of people with intellectual disabilities: Multiregional perspectives. *Family Relations*, 1–15.
- *Pavlopoulou, G. and Dimitriou, D. 2019. I don't live with autism; I live with my sister'. Sisters' accounts on growing up with their preverbal autistic siblings. *Research in Developmental Disabilities*, 88, 1–15.
- Pavlopoulou, G. and Dimitriou, D. 2020. In their own words, in their own photos: Adolescent females' siblinghood experiences, needs and perspectives growing up with a preverbal autistic brother or sister. *Research in Developmental Disabilities*, 97, 103556.
- *Petalas, M. A., Hastings, R. P., Nash, S., Dowey, A. and Reilly, D. 2009. "I like that he always shows who he is": The perceptions and experiences of siblings with a brother with autism spectrum disorder. *International Journal of Disability, Development and Education*, 56, 381–399.
- *Petalas, M. A., Hastings, R. P., Nash, S., Reilly, D. and Dowey, A. 2012. The perceptions and experiences of adolescent siblings who have a brother with autism spectrum disorder. *Journal of Intellectual & Developmental Disability*, 37, 303–314.
- *Pompeo, M. N. 2009. When your "problem" becomes mine: Adult female siblings' perspectives of having a brother with a disability. *Exceptionality Education International*, 19, 50–62.
- Poston, D. T., Turnbull, A., Park, J., Mannan, H., Marquis, J. and Wang, M. 2003. Family quality of life: A qualitative inquiry. *Mental Retardation*, 41, 313–328.
- *Rampton, T. B., Rosemann, J. L., Latta, A. L., Mandlco, B. L., Roper, S. O. and Dyches, T. T. 2007. Images of life: Siblings of children with down syndrome. *Journal of Family Nursing*, 13, 420–442.
- *Rawson, H. 2010. I'm going to be here long after you've gone' - sibling perspectives of the future. *British Journal of Learning Disabilities*, 38, 225–231.
- Rillotta, F., Kirby, N., Shearer, J. and Nettelbeck, T. 2012. Family quality of life of Australian families with a member with an intellectual/developmental disability. *Journal of Intellectual Disability Research : JIDR*, 56, 71–86.
- *Rossetti, Z. and Hall, S. 2015. Adult sibling relationships with brothers and sisters with severe disabilities. *Research and Practice for Persons with Severe Disabilities*, 40, 120–137.
- Rossiter, L. and Sharpe, D. 2001. The siblings of individuals with mental retardation: A quantitative integration of the literature. *Journal of Child and Family Studies*, 10, 65–84.
- *Sage, K. D. and Jegatheesan, B. 2010. Perceptions of siblings with autism and relationships with them: European American and Asian American siblings draw and tell. *Journal of Intellectual & Developmental Disability*, 35, 92–103.
- Samuel, P.S., Tarraf, W. and Marsack, C. 2018. Family quality of life survey (FQOLS-2006): Evaluation of internal consistency, construct, and criterion validity for socioeconomically disadvantaged families. *Physical & Occupational Therapy in Pediatrics*, 38, 46–63.
- Saxena, M. and Adamsons, K. 2013. Siblings of individuals with disabilities: Reframing the literature through a bioecological lens. *Journal of Family Theory & Review*, 5, 300–316.
- Schippers, A., Berkelaar, M., Bakker, M. and Van Hove, G. 2020. The experiences of Dutch fathers on fathering children with disabilities: 'Hey, that is a father and his daughter, that is it'. *Journal of Intellectual Disability Research : JIDR*, 64, 442–454.
- *Stalker, K. and Connors, C. 2004. Children's perceptions of their disabled siblings: 'She's different but it's normal for us. *Children & Society*, 18, 218–230.
- Stoneman, Z. 2005. Siblings of children with disabilities: Research themes. *Mental Retardation*, 43, 339–350.
- Thomas, C. 1999. *Female Forms: Experiencing and Understanding Disability*. Buckingham: Open University Press.
- *Tozer, R. and Atkin, K. 2015. "Recognized, valued and supported"? The experiences of adult siblings of people with autism plus learning disability. *Journal of Applied Research in Intellectual Disabilities : JARID*, 28, 341–351.
- *Tozer, R., Atkin, K. and Wenham, A. 2013. Continuity, commitment and context: adult siblings of people with autism plus learning disability. *Health & Social Care in the Community*, 21, 480–488.
- Turnbull, A. P., Brown, I. and Turnbull, H. R. 2004. *Families and people with mental retardation and quality of life: International perspectives*. Washington, DC: American Association on Mental Retardation.
- Vanderkerken, L., Heyvaert, M., Onghena, P. and Maes, B. 2018. Quality of Life in Flemish families with a child with an intellectual disability: A multilevel study on opinions of family members and the impact of family member and family characteristics. *Applied Research in Quality of Life*, 13, 779–802.
- *Vella Gera, J., Martin, G. M. and Camilleri Zahra, A. J. 2021. An insight into the lives of young siblings of disabled children in Malta. *Disability & Society*, 36, 58–80.
- Zuna, N. I., Turnbull, A. and Summers, J. A. 2009. Family quality of life: Moving from measurement to application. *Journal of Policy and Practice in Intellectual Disabilities*, 6, 25–31.
- Zuna, N., Summers, J. A., Turnbull, A. P., Hu, X. and Xu, S. 2010. Theorizing about family quality of life. In: R. Kober, ed. *Enhancing the quality of life of people with intellectual disabilities*. Dordrecht, The Netherlands: Springer, pp.241–278.