

Siblings of children with intellectual and developmental disabilities: Quality of life perceptions from Catalonia

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Abstract

Siblings' interactions and shared experiences influence their perceptions of quality of life. Recently, research about siblings of children with intellectual and developmental disabilities has been significantly expanded but data from Southern European countries is still missing. This research was carried out in Catalonia (northeast Spain) a region in the Mediterranean area with its own shared culture, language and traditions that equally embraces an important diversity of ethnicities and cultures. The main aim was to collect siblings' perceptions on quality of life from siblings' own voices. Semi-structured interviews were conducted with 14 siblings aged 5–11 years old and thematically analyzed using the following domains: joint activities; mutual understanding; private time; acceptance; forbearance; trust in well-being; exchanging experiences; social support; and dealing with the outside world. Siblings reported a variety of experiences in relation to having a brother or a sister with intellectual and developmental disabilities (I/DD), including unique characteristics of their quality of life perceptions. There were also some common factors amongst the siblings' experiences, such as the importance of being able to communicate properly with their brothers or sisters with I/DD. It emerged that having their own time with their parents was an important factor in their own development. This research echoes some siblings' beliefs that society needs to provide a conscious revision of values and ideas regarding disability. Implications for research and practice are described.

KEYWORDS

developmental disability, family quality of life, intellectual disability, siblings, siblings quality of life

Abbreviations: 22q11.2, 22q11.2 deletion syndrome; 5p-, cri-du-chat syndrome; ASD, autism spectrum disorder; DS, Down syndrome; FQOL, family quality of life; FXS, Fragile X syndrome; I/DD, intellectual and developmental disabilities; ID, intellectual disability; NGO, non-governmental organization; PIMD, profound intellectual and multiple disabilities; QOL, quality of life; SMS, Smith–Magenis syndrome.

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INTRODUCTION

Siblings often have a genuine, unique and powerful bond with their brothers and sisters, which is typically kept throughout the lifetime (Tozer et al., 2013). In their relationship, siblings learn to love, take care of each other and establish their own ways to communicate, play and interact (Cuskelly & Gunn, 2003; Diener et al., 2015). As Canary (2008) noted, siblings' relationships have an important role in identity construction. In fact, siblings' relationships represent the opportunity to develop skills and abilities in both siblings; promoting positive feelings like pride and joy (Vella Gera et al., 2021). However, negative feelings are also stated when one of the siblings in the dyad has intellectual and developmental disabilities (I/DD), such as guilt, jealousy or parental attention deprivation (Lemoine & Schneider, 2022). Frequently, siblings' daily interactions are influenced by different factors like parenting style, personality traits but also siblings' intellectual or developmental disability (Orsmond & Seltzer, 2007).

Families constitute in most cases the first social environment in the siblings' life promoting their development, identity construction and quality of life (Brown & Brown, 2004). Inside a family, individuals' quality of life (QOL) is in a constant interaction with the family's quality of life (FQOL) influencing and modifying each other (Zuna et al., 2010). In this dynamic interplay, the experience of disability within the family will affect the family members, their perceptions of quality of life and their interactions with the wider community (Boelsma et al., 2018).

Luijkx et al. (2016) investigated the positive and negative experiences of siblings of children with multiple disabilities, including severe intellectual disability, and suggested that having a brother or a sister with a disability affected siblings' general perceptions of quality of life. This research is aligned with other studies in the family quality of life field. For example, Moyson and Roeyers (2011) and Rillotta et al. (2012), noted the importance of investigating how siblings perceive and describe their quality of life. Moyson and Roeyers (2012) also asserted that young siblings should be asked directly to report on their experiences, in order to comprehend their quality of life. These authors, had proposed nine useful domains to describe siblings' quality of life: (1) joint activities; (2) mutual understanding; (3) private time; (4) acceptance; (5) forbearance; (6) trust in well-being; (7) exchanging experiences; (8) social support; and (9) dealing with the outside world.

In addition to the studies by Luijkx et al. (2016) and Moyson and Roeyers (2011, 2012) several studies with young siblings reported significant findings using

interviews as a data collection instrument (Kao et al., 2011; Stalker & Connors, 2004). Other studies have combined siblings and parental perspectives to explore experiences regarding disability (Cebula, 2011; Chan & Lai, 2016; Diener et al., 2015) and also the views of younger and older siblings (Carter et al., 2015; Rampton et al., 2007).

Additionally, the cultural environment where siblings live also influences their quality of life. As indicated in Schippers et al. (2015), families are embedded in sociocultural frameworks with values and traditions that may affect and influence their family quality of life. Consequently, investigating families and their members' realities in different contexts appears as a key issue (Hwang & Charnley, 2010; Ravindran & Myers, 2011; Tsai et al., 2016).

A recent systematic review of the literature about siblings of people with intellectual and developmental disabilities and their quality of life (Múries-Cantán et al., 2022) has shown that: (a) published data on young siblings from a quality of life approach is still limited and (b) the majority of reviewed articles were conducted in English-speaking or Western European countries. In particular, while some research on young siblings has been carried out in different Mediterranean countries (e.g., Findler & Vardi, 2009; Mouzourou et al., 2011) none appear to have been focused on the quality of life perceptions of young siblings in Southern Europe.

The present research was carried out in Catalonia, an autonomous region situated in the northeast of Spain. Nowadays, Catalonia has a cultural, religious and linguistic diversity that has permeated families' practices and beliefs (Giné et al., 2015). The research question that guided this research was: "How do young siblings aged 5–11 years old of children with I/DD living in Catalonia perceive and describe their quality of life as siblings? Due to the importance of family dynamics on siblings' life, parental perspectives are included to get their views on their children's relationships. Findings from this research are aimed to contribute to our understanding of siblings' perceptions and their lived experiences. Furthermore, they could be of interest for those working and researching with families of people with intellectual and developmental disabilities.

METHODS

Design

This qualitative study followed an inductive approach. The principles of thematic analysis as described in Terry et al. (2017) served as a guide in conducting the research and analyzing the data.

Participants

A review on the field of siblings of people with I/DD revealed that young children were the most under researched population group. Consequently, school-age children were selected to participate in the research. Semi-structured interviews were conducted with siblings of children with I/DD. In Catalonia and in Spain the total number of children with special needs matriculating to regular schools has been increasing due to policies promoting inclusive education. Nevertheless, still half of the students with special needs in Catalonia remain in special education schools. Participants were selected through four special education schools and two NGOs had facilitated the recruiting process. Also, a purposive sample of additional potential families was reached (Palinkas et al., 2013).

The recruitment documents sent to siblings and families were a colorful and illustrative flyer, which summarized research-related information that was comprehensible to siblings, along with an invitation letter to the parents. These documents were provided in Catalan and Spanish. The families willing to participate in the research were contacted by the first author via mail or a phone call to arrange a first meeting, which was an opportunity to meet the family and to explain more details and questions about the research. The verbal assent given by siblings and the signed consent from parents, were collected during the meeting.

Afterwards, the first interview was carried out (and audio-recorded) to find out about the sibling's world and to start building a trusting relationship that would be helpful during the research process. Finally, a total of 14 siblings, 6 females and 8 males, aged from 5 to 11 years old ($M = 8$ years; $SD = 2.14$), agreed to participate in the study.

A short questionnaire to collect demographic information was completed by the parents ($N = 13$). One mother declined completing the questionnaire but agreed to her child participating. The respondents were mothers ($n = 11$) and fathers ($n = 2$); they had completed higher education, had a paid job and were living in urban areas in the same house of a partner and their children. Most of the respondents considered that the monthly income was sufficient to support the family's needs, but some reported that there was a need to increase quality of life. Along with closed questions, some open-ended questions concerning the child with I/DD and the relationship between brothers and sisters were included to get the parental' views of the nature of siblings' relationship. Data from these questions is reported at the Results section. Demographic characteristics are presented in Tables 1 and 2. Pseudonyms are used to preserve the identities of the participants.

An effort was made to select a variety of families to get a more diverse rainbow of siblings' experiences and quality of life perceptions. To this end, the institutions were selected because of the particular characteristics of their

TABLE 1 Participant and brothers/sisters with I/DD demographic information

| Sibling participant ($N = 14$) | | | | Brothers/sisters with I/DD ($N = 13$) | | |
|----------------------------------|--------|-----|---|---|-----|--------------|
| Pseudonym | Gender | Age | Position in relation to child with I/DD | Gender | Age | Type of I/DD |
| Meritzell ^a | F | 5 | Younger | M | 12 | Severe ID |
| Xavier ^a | M | 5 | Younger | | | |
| Miguel | M | 5 | Younger | M | 9 | ASD |
| Guillem | M | 7 | Younger | F | 11 | 22q11.2 |
| Rafa | M | 7 | Younger | M | 10 | ID |
| Ivan | M | 8 | Younger | M | 13 | 22q11.2 |
| Nil | M | 8 | Older | F | 6 | DS |
| Joan | M | 8 | Younger | F | 15 | ID |
| Judit | F | 9 | Twin | M | 9 | ASD |
| Lilith | F | 10 | Younger | F | 14 | 5p- |
| Júlia | F | 10 | Older | M | 6 | DS |
| Beatriz | F | 11 | Younger | F | 13 | FXS |
| Jordi | M | 11 | Younger | F | 15 | PIMD |
| Tània | F | 11 | Younger | M | 15 | SMS |

Abbreviations: 22q11.2, deletion syndrome; 5p-, cri-du-chat syndrome; ASD, autism spectrum disorder; DS, Down syndrome; FXS, fragile X syndrome; PIMD, profound intellectual and multiple disabilities; SMS, Smith-Magenis syndrome.

^aTwins.

TABLE 2 Demographic characteristics of the families

| Variable | Parents (N = 13) |
|---|------------------|
| Age (n), range (years) | 34–51 |
| 30–40 | 2 |
| 41–50 | 10 |
| 50–60 | 1 |
| Gender (n) | |
| Female | 11 |
| Male | 2 |
| Relationship to sibling participant (n) | |
| Biological mother | 11 |
| Biological father | 2 |
| Type of family (n) | |
| Couple with 2–3 children | 11 |
| Large family up to 4 children | 2 |
| Education level (n) | |
| Less than primary education | 1 |
| Primary education | 1 |
| Secondary/higher education | 4 |
| Bachelor's degree | 4 |
| Postgraduate degree/PhD | 3 |
| Employment (n) | |
| Full-time or part-time | 11 |
| Others | 2 |
| Monthly income perception (n) | |
| Enough to support family's needs | 5 |
| Enough but could be better | 3 |
| Not enough to support family's needs | 5 |
| Type of area where living | |
| Urban | 8 |
| Rural | 5 |
| Cultural origin (n) ^a | |
| Catalan/Spanish | 11 |
| Other European countries | 2 |
| Latin America | 1 |

^aSome respondents indicated the cultural origin of their partners, thus the *n* adds up to more than 13.

focus population (i.e., higher level of students with ASD or NGOs centered on specific intellectual disabilities). Furthermore, we knew the selected schools well and this allowed us to have access to or inquire about the age range of children who we wish to interview. We went to the younger age group of people with disabilities, but this naturally led

to a varied age group of siblings without I/DD, providing some variability amongst the participants who participated.

Interviews

A total of 29 semi-structured interviews were conducted with siblings at their family homes. Depending on their age, some siblings were interviewed once, others twice and some three times. For example, younger children typically had more and also shorter sessions. On average interviews lasted 41 min ranging from 10 to 85 min. At the start of each session a comfortable environment was secured and a careful reminder of the details and goals of the research and of the confidentiality of the process was made.

The interview guide (see Table 3) contained three main themes: (1) the sibling's life history; (2) perceptions on their quality of life; and (3) the meaning of their experiences. These themes were based on those that guided the interviews by Moyson and Roeyers (2012).

Previous research has noted young children's abilities to report on their experiences is improved when provided with adequate support (Bachraz & Grace, 2009; Pyle, 2013). Accordingly, a set of resources were used in carrying out the interviews. For example, content from relevant books (Llenas, 2012; Ponce & Gallardo, 2016) was used, such as short graphic stories about siblings of children with disabilities and the emotions they might feel. Siblings were invited to show their toys or beloved objects. The interviewer was sensitive to detecting whether siblings required more time to deal with particular emotionally charged moments during the interviews. Parents were previously advised that siblings could be affected emotionally following the interviews. In case parents or others had follow up questions, a telephone number and email address were provided for necessary support.

Quality procedures

To assure the adequacy of the questionnaire and the interviews guide, both were pilot tested with three families that met the eligibility criteria. Parents and sibling participants were requested to assess the questionnaire and the interviews (e.g., length, appropriateness of the questions) through open-ended questions. No significant changes were recommended. Data from these families were included in the analysis.



TABLE 3 Interview guide

1. The sibling's life history

- Could you share with me some important events that happened in your life?
- Are there some important events that happened to you because you're a sibling?
- What do you think about having a brother/sister?
- Do you like to spend time with your family?
- How about the school?

2. Perceptions on their quality of life

- What do you think about your brother/sister?
- When did you realize your brother/sister was different?
- How is it for you being a sibling in this particular family?
- Could you tell me about moments when you like to be a sibling?
- What do you like the most about your life?
- Is there anything you think should be better to change in your life?
- Do you think you and your parents have enough help and support from others?
- How is your relationship with your brother/sister?
- How do you used to communicate with your brother/sister?
- How is your brother/sister relationship with your parents?
- What do you like to do the most with your parents? How much time do you spend with them?
- Would you like to change something about your relationship with your parents?
- Have you ever met other brothers and sisters with siblings with I/DD?

3. The meaning of their experience

- Did you ever have to do something special because you have a brother/sister?
- Do you think having a brother/sister with I/DD has influenced your life in some way?
- How do you feel being a sibling of a child with I/DD?
- What do you need as a sibling to be happy?
- Is there anything I have forgotten to ask you about?

The combination of different methods of collecting data- the parents' questionnaire, the interviews and the observational and field notes - allowed for some comparison of data between parents and siblings.

Data analysis

All the interviews with siblings were audio recorded and transcribed. We decided to use the features of Atlas.ti (2002–2019) as it was considered an easier, faster and visual method to codify our data. This computer-assisted

software for analyzing large amounts of qualitative data has facilitated the coding process.

First of all, we familiarized ourselves with the collected data. We started the transcription of the interviews as soon as we initiated the data collecting process. Some of the observational notes we made during the transcription served to influence and improve the subsequent interviews with the other participants, by reformulating particular questions or giving more prevalence to some of them. At the same time, reflective and field notes made after conducting the interviews, were also taken into account. This material was used alongside the codification process and served to enrich the interviews with relevant information. Regarding the setting of the interviews, for example, the participants' various behavior during the sessions was noted and any personal information about their families that might assist the broad understanding of the collected data.

Having transcribed approximately half of the interviews, we started the codification process. We conducted a systematic and iterative process of coding any piece of data that had relevance to the research question. Codes could be a word or a short sentence highlighting the meaning of that specific piece. We generated the codes in an inductive way. Even when not required in the type of thematic analysis that we were performing, we decided to use a coding reliability measure. Thus, 10% of the interview data was subjected to an inter-coder agreement with an independent researcher, which resulted in a 79% of initial agreement. Disagreements were then discussed in order to achieve a final common view.

A first set of themes was developed from the final group of codes. Definitive themes and their interrelations were discussed between the first, second and last author until a consensus was reached. After having achieved this point on the analysis, we considered the paper by Moyson and Roeyers (2012). This seemed to represent an important background considering earlier work. From this, we adopted their nine domains of siblings' quality of life (mentioned in the Introduction), to report our findings.

Ethical issues

Ethical approval of the project was sought and granted by the Ramon Llull University Ethics Committee (reference number 1819001D). Siblings' choice to participate freely was fundamental. Consequently, their assent was verbally collected in the first meeting. Siblings were informed that they could withdraw from the research at any time without any kind of inconvenience.

Due to the sensitive nature of the discussed topics authors took time to ensure the siblings were feeling safe and comfortable throughout the data gathering process. The interviews took place in familiar environments of the

parental home. The researcher and the siblings were alone and with no interruptions. The parents and children had already given consent and the parents remained in the home. Additionally, siblings were asked if there was any information they did not want to be shared with their parents. This was important as there was a debriefing session that was performed with parents after the siblings' interviews.

RESULTS

The research findings¹ are reported using the nine domains of siblings' quality of life described by Moyson and Roeyers (2012) (see Table 4).

Joint activities

A majority of siblings ($n = 10$) talked about joyful moments and activities shared with their brothers or sisters with I/DD. These activities were mainly playing, doing sports or watching TV. Four siblings indicated they did not do activities together with the sibling with a disability since they had different interests; for instance, a brother reported not being much involved with her sister with Down syndrome because "she likes to play with dolls and be bossy" (Nil, 8 years old). Only five of the 14 siblings recognized the need to adapt activities according to their siblings' interests and created funny moments for them:

"We jump pretending to hurt ourselves and she laughs, we throw things at her and she laughs, if she breaks things or throws things at you, she laughs... we play like this" (Jordi, 11 years old)

Four siblings reported care-related tasks as joint activities, such as dressing or looking after their brothers or sisters with I/DD while outside, and one sister indicated her pleasure in doing such activities.

TABLE 4 Nine domains of sibling quality of life (Moyson & Roeyers, 2012)

| |
|-----------------------------------|
| 1. Joint activities |
| 2. Mutual understanding |
| 3. Private time |
| 4. Acceptance |
| 5. Forbearance |
| 6. Trust in well-being |
| 7. Exchanging experiences |
| 8. Social support |
| 9. Dealing with the outside world |

Mutual understanding

Almost all participant siblings ($n = 13$) developed their own way to interact and communicate with their brothers or sisters with I/DD; using words, gestural communication, pictograms or facial expressions. Two sisters referred to understanding their brothers or sisters even better than their parents:

"I am the one in my house who understands her best. When someone does not understand her, they always ask me: What does Susana say? Susana explains it to me, and I tell them." (Beatriz, 11 years old)

Four siblings seemed to "infer" they knew what their brothers or sisters want or feel with some suggesting it is because of their shared bond.

"She communicates but sometimes it makes me sad that she cannot express herself, she gets angry and hits herself [...] I don't know much about sign language, because there are a lot of signs...but sometimes I understand her as a sister, I mean, sometimes we are connected..." (Lilith, 10 years old)

Private time

Five siblings reported it was important to have private time and to have their own bedroom; although two sisters reported wanting to sleep with their siblings with disability at night. Three sisters valued having spaces without their brothers or sisters and spend private time with their parents:

"Inside the house Claudia is the one who has all the attention but outside, maybe it's me." (Lilith, 10 years old)

"For example, at the dentist where I know I'll have a bad time, I don't like him to be there because I need my mother to be just for me." (Júlia, 10 years old)

Acceptance

Siblings developed their own understanding of what is going on with their brothers or sisters with I/DD, with one sister recognizing: "I didn't know a lot, I just accepted him and that's it" (Tània, 11 years old). Three



siblings reported having a “normal” relationship with their siblings with I/DD, not different from the relationship with siblings without a disability.

A sister suggested that knowing the “name” of her sister’s disability has helped her to understand her sister’s disability and to be able to give an answer to those asking about her. Furthermore, five sisters showed an understanding of different parental treatment towards their brothers or sisters, while craving parental attention for themselves:

“It’s like they’re paying more attention to him, I understand, but they also have to pay a little bit of attention to me, you know. Because I’m not... invisible.” (Judit, 9 years old)

“I’m fine as a sister, what I dislike is that they leave me as a second dish.” (Tània, 11 years old)

Two sisters recognized being positively influenced by their brothers or sisters with I/DD, like being more open-minded and more sensitive to other people with disabilities. None of the 14 siblings reported being influenced in a negative way.

Forbearance

Five siblings indicated needing more patience and self-control than other siblings when having a brother or a sister with disability. Different situations were mentioned, like having to give more frequent explanations to their brothers or sisters with I/DD, having to adapt themselves to their siblings needs or when dealing with specific circumstances like echolalia or tantrums.

A sister when asked about what she considered important from her experience as a sister in regard to family relationships said:

“More than anything, I think he is a person like us [...] I treat him like a normal brother, although sometimes I have to make my parents be more attentive because he has autism, right? I also have to do special things, such as spending more time studying alone because he needs help too.” (Judit, 9 years old)

Trust in well-being

Five siblings reported fearing something bad could happen to their siblings, like others taking advantage of them

due to their disability, falling outside the bed, or hurting themselves. A sister mentioned being happy to share her bedroom with her sister because “I’m feeling safe that she is alright and nothing happens to her” (Beatriz, 11 years old).

Siblings with I/DD having medical issues also affect sibling’s well-being, with a few siblings ($n = 3$) indicating being worried about their brothers or sisters’ health but also tired of attending their brothers or sisters with I/DD’ medical appointments.

“The moment I suffered a lot was when he was 6 months old that he had a heart surgery and, of course...I cried when they told me [...]. He was my brother and I didn’t want anybody to touch him. [...] Then, my parents gave me things to listen to his heart, so that I would lose my fear.” (Júlia, 10 years old)

A few siblings ($n = 5$) referred to feeling sad for their brothers or sisters with I/DD because of experiences they were not able to have or difficulties they faced daily, due to their condition or limited abilities.

“The sadness is because sometimes when we are going to do cool things, like for example cool trips, she can’t join us.” (Jordi, 11 years old)

Exchanging experiences

Only four siblings reported wanting to meet other brothers or sisters who had siblings with I/DD in order to share similar experiences and to feel understood by them. A brother explained why he would like to meet other siblings:

“Because while I don’t know anyone who has a brother like this, I get sad because it seems that only my brother has a problem.” (Rafa, 7 years old)

Two sisters already knew other siblings of children with I/DD and noted being happy to share activities and experiences with them. Three siblings wanted to share some advice to other siblings of people with I/DD such as having patience, looking for useful resources to express their emotions and talking with their parents.

Social support

Half of the siblings reported relying on their parents to know what was going on with their brothers or sisters

with I/DD. Parental explanations helped them to understand and normalize their siblings' behavior:

“I was told that he was different from the others, that he had autism and that I don't have to be afraid if my brother would do weird things and people stare weird at him” (Judit, 9 years old)

“Down syndrome is something that occurs inside the body, which when you are born makes it difficult for you to do things... and doesn't let you relate like others do.” (Nil, 8 years old)

Few siblings ($n = 5$), mentioned support they received from extended family, like fixing toys broken by their brothers or sisters with I/DD or playing with their siblings:

“Robert had the best relationship with my grandfather [...] I don't know why but for some reason they connect very well, you know? They are always playing together... my grandmother also plays a bit with him but is mostly my grandfather the one with whom Robert wants to play” (Júlia, 10 years old)

Two of them, specifically referred to the relationship with their cousins, involving moments of playing while taking care of the child with disability:

“Two of us play together while one keeps an eye on Marta [...] because she could run away” (Guillem, 7 years old)

A few siblings ($n = 6$) commented that having friends to trust and feeling understood by them was important. Professional support for their brothers or sisters with I/DD was also beneficial for siblings ($n = 3$) as they could spend more time with their parents, learn new ways to communicate with their brothers or sisters or improve their knowledge about disability.

“That's why we have this assistant so my mom can dedicate time to me” (Lilith, 10 years old)

Dealing with the outside world

Half of the siblings mentioned different types of experiences when at the school or when interacting with the

larger community. Four indicated being questioned and having to give explanations about their brothers or sisters with I/DD. In this sense, one sister referred to how teachers could help siblings at school:

“There are a lot of people who...well now not so much because now everyone knows Robert has Down Syndrome although some do not know much what it means, but well, I leave it to be. But before, they asked me a lot: “What is it?” and of course, I didn't know how to explain it to them because I'm not an expert either and, I don't know, maybe teachers could explain it a bit in order for others to get informed too.” (Júlia, 10 years old)

Three siblings also reported being stared at by strangers; yet a brother from a rural city, noted that people could be nicer and respectful when going out with his sister with PIMD. For a couple of siblings, dealing with the outside world meant dealing with physical barriers, like narrow sidewalks or occupied special parking lots by people without disability.

Finally, a sister reflected about the stigma her brother may suffer due to the invisibility of autism, including being called bad words, not being accepted because of his interests or being stared at in the streets. That's why, she called for a collective mind-set change:

“People also have to start understanding that there are people different from them, not only for the physical aspect but for the inner aspect.” (Judit, 9 years old)

Parental' perceptions on siblings' relationships

The questionnaire answered by the parents ($N = 13$) reported significant information about parents' perceptions of their children' relationship. Almost half of the respondents ($n = 6$) commented that their children used to fight and argue.

“They get along well and love each other a lot, but there are always a lot of fights and discussions.” (Mother, 39 years old)

Five respondents reported their children had a nice relationship involving feelings of love and all the participants indicated their children used to share time and activities together. Two mothers reported feelings of jealousy by their children with no I/DD and explained this was due



to different parental treatment in responding to the child with I/DD' health issues. A few respondents ($n = 3$) indicated how certain characteristics associated with the brother or sister with I/DD might impact the quality of the siblings' relationship, such as communicative disorders or the child with I/DD having a tendency to hit or invade the personal space of their siblings. Yet a few respondents ($n = 3$) noted how the difficulties of their children with no I/DD of comprehending their brothers or sisters' needs, could affect their relationship as well:

“Although [*their relationship*] is good I think that the fact that she doesn't speak fluently, disturbs Nil and he doesn't get along well. They love each other and they are jealous of each other. They also band together and play together.” (Mother, 42 years old)

The questionnaire asked about some aspects, such as interests or worries, that siblings might have regarding their brothers or sisters with I/DD. Some respondents ($n = 4$) noted different worries of siblings concerning their brothers or sisters with I/DD. For example, being worried about their well-being, their eventual death, their difficulties in doing age-related tasks and about their future after their parents' decease.

Finally, during the debriefing sessions at the end of the process, a few ($n = 5$) parents commented that taking part in the interviews appears to help their children understand their brothers or sisters with I/DD. They also reported some emotional reactions on siblings after these sessions.

DISCUSSION

The aim of this study was to become more informed about the quality of life's perceptions of siblings of children with I/DD living in Catalonia. Siblings' data was enriched with the parental views on siblings' relationships- showing different feelings and perceptions.

This study makes several contributions to the literature. It is relevant to note that children in this study could relate their experience of having a brother or sister with I/DD from their own point of view. Further than relate, siblings were able to describe, in a mature and sensitive way, their inner perceptions and lived experiences of having a brother or a sister with I/DD. Barak-Levy et al. (2010) suggested that asking children themselves resulted in relevant and useful information about their own experience. In fact, interviewing siblings in the context described in this article highlights, despite their age, information about their quality of life and in this

instance including their capacity of young siblings to report inner experiences. However, there are certain issues that must be taken into consideration.

First of all, it was important to develop rapport while the sibling and interviewer got to know each other. In this research this was assured by spending time with the siblings without I/DD prior to the more formal section of the study. For example, talking about their hobbies and interests using plain language, drawing and playing (Irwin & Johnson, 2005). The interview structure should be flexible enough to adapt to the circumstances that may occur during the formal interview (e.g., external interruptions, unexpected relatives' visits) and to the needs that children may have (e.g., time to get involved, movement needs).

We then followed a set of questions that served as a “guide” for the interviews, which we expected to facilitate the openness of the discussion including welcoming interjections or topics siblings might bring up (Cameron, 2005). In this sense, it was important to let the participants talk freely about whatever they considered from the interview questions. In the case of younger children, it was thought necessary to provide opportunities for drawing, games, toys and other prompts to stimulate the conversation (Cameron, 2005). This was found to be the case with the youngest participants (from 5 to 8 years old). Additionally, on some occasions the active presence of parents prior to the formal interview was useful to introduce new related topics that triggered some memories in the children (Irwin & Johnson, 2005).

The results demonstrate that children have their own voice and agency and this information should be useful to researchers, school teachers and other practitioners who could then provide support and insight which is relevant to all members of the family. Likewise, Luijkx et al. (2016) noted that siblings' reports differ from those of their parents when asked about their quality of life. This is consistent with an ongoing concern in the FQOL field that it is desirable to collect the views of all family members, since we already know that family members may have somewhat different perceptions from each other (Francisco Mora et al., 2020; Gardiner & Iarocci, 2015; Wang et al., 2006).

The social contexts where siblings live are influenced by cultural values that affect the social response to disability. For instance, when siblings report experiences linked to stigma under the “dealing with the outside world” domain, such as being stared at by strangers, or disrespectful behavior towards people with I/DD and their needs, such as occupied reserved parking lots, they are reflecting about the struggles they face when interacting with the wider community. Siblings are aware of the way their brothers or sisters do not always fit into the norms and values of society. These results are in line with

those of Boelsma et al. (2017), who found that not having the support and consideration from those in the immediate family and the local society where they were living, negatively impacted their FQOL. On the other hand, good relationships within the family unit and the positive role played by the extended family were important for siblings, something noted as well in other studies conducted in Southern Europe (Mouzourou et al., 2011).

The nine domains of sibling's quality of life by Moyson and Roeyers (2012) have proved useful in reporting siblings' perceptions. Results from the present study have shown similarities with those in Moyson and Roeyers (2012) and Luijkx et al. (2016), with siblings reporting both positive and negative experiences as a result of having a brother or a sister with I/DD. The "joint activities" and the "mutual understanding" domains received the highest number of positive references from siblings, demonstrating the importance of being able to spend quality time with their brothers or sisters with I/DD and to establish successful and enriching interactions with them.

The "acceptance" domain seems to be characterized by the importance of siblings referring to knowing of their brothers or sisters' I/DD. However, it is interesting to note the ambivalence presented on sibling's reports. Even when accepting and understanding a different treatment to their brothers or sisters due to their disability, this different treatment may not be well accepted. Something similar is found in Luijkx et al. (2016), where siblings reported their difficulties in accepting their brothers or sisters' disability because of the related difficulties they might have. We can perhaps infer that the acceptance process would oscillate and evolve during the sibling's life. Regarding the "exchanging experiences" domain, just a few siblings declared willing to meet other siblings in their situation, which differs from the findings of Moyson and Roeyers (2012). However, siblings indicated on the "social support" domain the importance of receiving a diversity of support from relevant people, in line with Moyson and Roeyers (2012).

Despite the usefulness of these domains, key aspects of siblings' perceptions have not been properly addressed. Siblings reflections denote the importance of family' dynamics and family interactions on their reported well-being. As defined by Zuna et al. (2010) "family quality of life is 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). Due to this dynamic and its interactive nature, disability could not be considered as a single outcome to explain the quality of life perceptions of siblings or of the other members of the family (Boelsma et al., 2017). Further exploration of siblings' experiences, such as the influence of family dynamics on the relationship between the siblings, including the siblings' roles, is necessary.

The information from the questionnaire answered by the parents, supported to some degree the data from siblings, although there are some differences that are important to remark. For instance, respondents referred to the fights and arguments their children used to have, something that was not equally highlighted by siblings. Parents respondents indicated feelings of jealousy amongst their children while this was not seen in the siblings' data. In general, parental responses seemed to be focused on the "negative side effects" that having a brother or sister with I/DD might have on siblings, rather than the more "balanced" views that siblings reported.

Strengths and limitations of the study

One of the strengths of this study is the wide variability of diagnosis amongst the brothers or sisters with disability and simultaneously the similarities of quality of life' perceptions amongst siblings. The debriefing sessions with parents after the interviews are another strength of the study. They represented an opportunity to discuss issues concerning the siblings and to give feedback from the sessions.

This research had a relatively small purposive sample. Despite this, the reported findings add to those from Moyson and Roeyers (2011, 2012) and Luijkx et al. (2016) and, as explained in Brown (2016), when "the research is repeated in various situations in different countries and the results are similar, then the data should surely be taken seriously and acted upon" (p. 3). Consequently, the findings that we present must be considered as part of a bigger picture that is beginning to provide information on siblings' quality of life perceptions.

Another limitation is that parents were the ones deciding to participate. While this is the general norm when researching with minors, it implies that siblings' voluntary participation was not guaranteed at first. The authors had to make conscious efforts to collect siblings informed consent and to assure their willingness to participate.

This study was limited to the exploration of quality of life' perceptions of siblings without I/DD. At this stage, we did not collect the perspective of the brother or sister with I/DD. This is indeed important for further research which should be undertaken to explore their quality of life as siblings. Given their limited communicative and cognitive abilities, creative and flexible ways to get to know about their perceptions will be needed. In addition, it would be interesting to look at the perspective of the different members of one family unit, collecting the similarities and divergences that may appear.

Implications for practice and future research

These findings have important implications for families, siblings and children with I/DD. Families could be interested in knowing about the balanced perspective that siblings offer regarding the experience of disability, which should positively influence family quality of life. For siblings, knowing about how other siblings without I/DD felt about the experience of family life, might help them put things into perspective and provide support as they could discover not being alone in their feelings and circumstances. At the same time, it is a way to valorize themselves as they realize the important role they have in their families. Children with I/DD may benefit from these research findings, given the siblings' relationship power and the commitment of these young siblings towards them. This information may help parents to obtain greater insight and have a positive impact on family dynamics.

This research supports the need in the QOL/FQOL field for more research conducted with different populations and in multiple countries and situations (Brown, 2016). Although the current research has a limited scope due to its culturally situated characteristics, it is important to keep collecting the voices from those in the margins (due religious, linguistic, gender or age-related reasons) in order to depict a more realistic image of FQOL.

We have seen the importance of finding out about children's views. Accordingly, more research on this topic needs to be undertaken that leads to practical ways to collect and take into account young siblings' perceptions. Finally, it is recognized that this particular group of siblings is an important group to examine, and this needs to be further followed up across the age range because the results may differ considerably over time.

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CONFLICT OF INTEREST

No conflict of interest has been declared.

ETHICS STATEMENT

Ethical approval of the project was sought and granted by the Ramon Llull University Ethics Committee (Reference Number 1819001D).

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ENDNOTE

¹ The full list of quotes may be obtained by writing to the first author (olgamc1@blanquerna.url.edu).

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