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The Experiences of Latino Siblings of Children with Developmental Disabilities

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Abstract

Objective—This qualitative study explored the experiences of Latino siblings of children with developmental disabilities.

Methods—Parents and typically developing siblings from 15 Latino families with a child with a developmental disability participated in separate interviews.

Results—Using Consensual Qualitative Research methodology (Hill, Thompson, & Williams, 1997), domains reflecting siblings' relationships, emotional experiences, and communication about the disability were identified. The child's need for caregiving was a prominent topic in the sibling and parent narratives. Parents reported concerns about siblings' experience of differential treatment whereas siblings reported concerns about restricted social activities because of their brother/sister.

Conclusions—Including multiple informants revealed commonalities and differences in parents' and siblings' perspectives on the impact of a child's disability. The importance of considering sibling adaptation in sociocultural context is discussed.

Keywords

siblings; child disability; Latino families

Introduction

There is growing literature on the psychological adjustment of typically developing siblings of children with developmental disabilities. Much of the research is based on behavioral report measures. Rossiter and Sharpe's (2001) quantitative review indicated that siblings of children with developmental disabilities are at increased risk for adjustment problems. However, siblings display a range of responses to a child's disability. The authors noted that a range of methods such as observational, qualitative, and longitudinal research designs was needed to supplement self-report measures.

Qualitative research allows for in-depth examination of siblings' experiences. Through interviews, family members provide their perspective on their personal situations. Interview

studies involving siblings of children with various disabilities have revealed some common experiences across studies. Characteristic of typical sibling relationships, siblings of children with disorders describe their interactions with their brother/sister as having both positive aspects such as affection for each other, and negative aspects such as quarrelling (Mascha & Boucher, 2006; Stalker & Connors, 2004). Negative aspects reflect the nature of the child's disorder. For example, siblings of children with autism reported being affected by the child's challenging behaviors (Mascha & Boucher, 2006). Most siblings reported discussing their concerns about their brother/sister with their parents (Opperman & Alant, 2003; Pit-Ten Cate & Loots, 2000).

Some interview studies with parents of children with various diagnoses have included discussions about typically developing siblings. One theme that has emerged has been parents' efforts to minimize the impact of the child's disability on the sibling. Parents report efforts to protect siblings by not talking to them about the child's disorder (Canary, 2008; Foster et al., 2001). They report trying to normalize their situation (Snell & Rosen, 1997) and to minimize interruptions to the siblings' routine (Honey & Halse, 2006).

Multiple factors influence parenting practices and siblings' adjustment to a child's disability including child and family characteristics and cultural context. Most research has been based on Caucasian American and European samples. Ethnic and racial minority populations are underrepresented and the cultural context of sibling adaptation to disability is rarely considered (Lobato, Kao, & Plante, 2005).

Latinos are the fastest growing minority group in the United States (U. S. Bureau of the Census, 2006). While Latinos are a heterogeneous group, most Latino subgroups share some cultural values. Magana's research (Magana 1999; Magana & Smith, 2006) on Latino parents of children with developmental disabilities emphasized the cultural value of familism. Familism is a cultural construct that places priorities of the family over the individual and is characterized by interdependence and duty to the family (Marin & Marin, 1991). In her study of Puerto Rican families with a young adult with mental retardation, Magana (1999) considered family members' participation in caregiving to embody the value of familism. She found that mothers reported siblings to have more involvement than fathers in the daily care of the individual with mental retardation. However, siblings were not included as study participants. The importance of family support in Latino families has been highlighted but often only the parents participate in research (Blacher & McIntyre, 2006). For example, interview studies with Latino families of children with disabilities have focused on parents' adaptation to the child's needs (Hughes, Vale-Riestra, & Arguelles, 2008; Skinner et al., 1999).

The aim of the current study was to explore the experiences of Latino siblings of children with developmental disabilities through sibling and parent interviews. Since little is known about Latino siblings of children with disabilities, the present study used the Consensual Qualitative Research (CQR) method (Hill et al., 1997; 2005) which is useful for investigating topics that have not been well explored.

Method

Participants

The sample consisted of members of 15 families with a child with a developmental disability. All 15 mothers (ages 27 – 43 years old, mean age = 36.5 years) and 1 father (36 years old) participated. The 17 typically developing siblings (10 girls, 7 boys) were 8 to 14 years old (mean age = 10.4 years). In two cases, two siblings from the same family participated. The children (7 girls, 8 boys) with the disability were 3 to 18 years old (mean

age = 9.5 years). The majority of sibling-child pairs were of the same gender (35% two girls, 35% two boys). The majority of siblings were the first (41%) or second (29%) born in the family and half (53%) of the siblings were older than the child with the disability. The age difference between the sibling and child ranged from 1 to 10 years (mean age difference = 4.2 years). All of the children had developmental delays and had the following primary diagnoses: intellectual disability or developmental delay (47%), physical disability such as cerebral palsy (40%), or neurological disorder such as seizure disorder (13%). The mean length of time since diagnosis was 7.5 years.

Just over half of the families (60%) were two-parent households and most had two (33.3%) or three (33.3%) children. The median annual income for the sample was in the \$20,000 to \$29,999 range. Families self-identified as Puerto Rican (40%), Dominican (27%), Central or South American (27%), or Mexican (6%). Using the standard English or Spanish translation of the Short Acculturation Scale (Marin, Sabogal, Marin, Otero-Sabogal, & Perez-Stable, 1987), parents completed the four questions regarding language usage using a 5-point Likert scale ranging from 1 (*only Spanish*) to 5 (*only English*). Responses were averaged across the four items and higher scores reflect greater acculturation. The parents' acculturation scores ranged from 1 to 3 (mean score = 1.95, standard deviation = .59) reflecting low levels of English usage and acculturation.

Researchers

The research team consisted of three faculty level clinical psychologists, one of Asian descent, one of Hispanic descent, and one of French-Canadian descent, and one post-doctoral child psychiatry fellow of Hispanic descent. All team members had clinical and research experience with qualitative techniques and multi-cultural patient populations. Prior to beginning the study, the research team discussed their biases and expectations. All of the researchers have siblings and their personal experiences may have influenced their perspectives on sibling relationships. We expected differences in parent and sibling reports about siblings' experiences and therefore we included both as informants in the study.

Measures

Semi-structured interviews were developed in English and translated to Spanish using a combined back-translation and bilingual translation committee consensus method (Matías-Carrello et al., 2003). We developed the interview based on our clinical experiences with siblings of children with disabilities (Lobato & Kao, 2002). The interview questions were organized around the topics of communication and experiences of living with a child with a disability. Siblings were asked to describe their brother/sister and the disability. They were asked whom they talk to about their brother/sister and what they talk about, how they and their brother/sister got along and what they did together, and how the disability has affected them (e.g., "How did you learn what you know about your brother/sister's *disability*?", "How has having a brother/sister with *disability* positively affected you?"). The final question asked siblings what advice they would give to another child who has learned that their brother/sister has a disability. Responses to this final question were considered separately and not included in the CQR analysis. The parent interview was composed of questions that paralleled the sibling interview questions to obtain parents' perspective on siblings' communication and interactions, and the impact of the disability on the sibling (e.g., "What kinds of things do you and *sibling* talk about regarding *child* and his/her *disability*?", "How big of an issue do you think that *child's* special needs are in *sibling's* life?").

Procedure

Families were recruited by a bilingual, bicultural research assistant of Hispanic descent who attended hospital-based clinics and community agencies serving children with disabilities and their families. The research assistant approached families and invited them to participate in the study. Eligible families who agreed to participate were scheduled for interviews. All participants provided written consent and assent before their participation in the study, which had approval from the hospital Institutional Review Board.

The research assistant and second two authors conducted the interviews. Parents and siblings were interviewed separately in the language of their choice with 80% of parents and 12% of siblings responding in Spanish. The interviews were audio taped, transcribed, and translated using the bilingual translation committee consensus method.

Data Analysis

The CQR method was used to analyze interviews via a consensus method (Hill et al., 1997; 2005). Content of the interviews was organized into domains and categories. Domains are the primary level of organization and are based on common themes that appear in the transcripts. As the second tier of organization, categories reflect core ideas and use the words of the participants as a more direct guide.

The first two authors served as primary coders and the second two authors served as auditors. The primary coders developed the initial list of domains and categories based on review of the interviews. The research team coded a randomly selected sibling and parent transcript using the initial list. After reviewing the coding of these two transcripts, the research team revised the domains and categories. Next, the primary coders independently coded the remaining transcripts and then worked together to further modify the domains and categories. Differences in coding were discussed with the auditors and the research team developed a consensus version of the domains and categories. Finally, the auditors independently reviewed two representative parent and sibling transcripts to verify that the coding appropriately reflected the data.

Using the finalized list of domains and categories, frequency counts were obtained for each category. Per the CQR method (Hill et al., 2005) the categories were defined as *general* (present in all or all but one of the cases), *typical* (present in more than half the cases), and *variant* (present in just under half of cases). *Rare* categories were those found in only a few cases and were not reported here.

Results

Sibling Interviews

Examination of the sibling interviews yielded five domains reflecting their communication, relationships, and emotional experiences related to living with a child with a disability. See Table 1 for the categories, frequencies, and examples for the domains from the sibling interviews.

Sibling Communication about the Disability—All 17 siblings reported that they talk to their mothers about the child and 7 siblings reported that they also talk to other family members, primarily their fathers. They typically reported wanting to know more information about the child's problems. For example, an 11-year-old brother said, "I asked my mom. She tells. [I] ask her about what he [child] has. I don't know about him still." One typical category and one variant category also emerged related to siblings talking about the child's condition and talking about the child's negative behaviors.

Sibling-Child Relationship—Siblings typically reported positive qualities about their relationship with the child, and most identified activities they liked to do together. For example, a 12-year-old sister stated “we have a lot in common - same movies, [we] watch a movie together, [I] share a room with her.” Siblings typically reported negative experiences including descriptions of the child’s intrusive or aggressive behaviors such as “He’s always hitting me, always messing up my bed, always messing up my homework” (8-year-old brother). Siblings typically gave accounts of providing care, supervision, or teaching to the child. An 8-year-old sister reported that “I stay home and make sure he [child] is okay, I try to help him with his school work”, and “I take care of him when my mother is doing other things.”

Sibling-Peer Relationship—Siblings typically reported that the child’s problems negatively impacted their peer relationships. They described not being able to interact with peers because of their caregiving duties (“Can’t go outside, have to help my mom figure out what [child] wants”, 8-year-old brother), or because of the child’s behaviors (“Can’t call my friends, she takes the phone [and] says things”, 9-year-old sister).

Sibling Positive Feelings—Siblings typically reported positive feelings about their relationship with the child. For example, a 9-year-old sister said, “When she [child] hugs me I feel safe with her. I think she feels happy because I’m her best friend, sister”. Siblings also typically reported positive feelings about providing care for the child such as “It’s great, better than staying by yourself in your room” (12-year-old sister).

Sibling Negative Feelings—The siblings’ negative feelings domain yielded four variant categories. Siblings reported feeling annoyed and embarrassed by the child. They expressed anger and disappointment about not being able to be with their friends. They also expressed being angry and upset about their caregiving activities. A 12-year-old sister shared that “Sometimes I get upset a lot ‘cause since I was little [mother] always wanted me to take care of my sister. It makes me feel like I have a huge responsibility.” Finally, siblings reported feelings of sadness and sympathy for the child because of the disability. An 11-year-old brother commented “Very sad to have a brother like that.”

Sibling Advice Question—When asked to give advice to another sibling in a similar situation, 11 respondents offered advice specifically on how to care for their brother or sister. An 11-year-old brother suggested, “Take good care of him, give him love, talk to him, and help out nurses so [they] know where everything is. Spend time with him. Be a good brother or sister.”

Parent Interviews

Coding of the parent interviews resulted in four domains reflecting their perspective on their parent-sibling communication, sibling relationships, and siblings’ feelings about the child with a disability. See Table 2 for the categories, frequencies, and examples for the domains from the parent interviews.

Parent-Sibling Communication about the Disability—Two variant categories emerged from the domain about parent-sibling communication. Parents’ conversations with siblings focused on the etiology of the disability and on the child’s prognosis. One mother said that her 12-year-old daughter “starts to ask me about her sister, that she is not normal like other kids. I started telling [sibling] that it was something that would pass and that was not the truth. It is a disability that we don’t know will have a cure.”

Parent Explanations to Siblings about the Child's Disability—Parents typically reported that they made active efforts to improve siblings' comprehension of the child's disability. One mother said "I explain his [child's] problem, try to understand him, try to help him in what we can, try to understand his problem". A variant category reflected parents' explanations of the siblings' caregiving responsibilities. Parents emphasized the need for siblings to understand why they have to help the child. One mother said "I tell [sibling] you have to be careful and understand [child] is the youngest and she doesn't know. She needs tending to. We have to tend to her first and you help too."

Parent Perspective on Sibling Relationships—Parents typically reported that the sibling and child had positive interactions such as playing together and negative interactions such as fighting with each other. They also typically described how siblings provided care for the child. One mother said that "she [sibling] cares for him [child], she helps him, she helps him take his medicine, she makes sure he doesn't fall, she is like another mother."

Parents typically shared their concerns about the siblings' experience of differential treatment because of the child's needs. Most parents reported feeling that they did not have enough time to spend with siblings. One mother commented "the fact that [child] needs a lot of attention is a big thing for [sibling] because he's the youngest and he always wants attention and sometimes I cannot give it to him because I'm working with the other one."

Parent Perspective on Siblings' Feelings—Parents typically reported that siblings expressed negative feelings towards or about the child such as anger, embarrassment, and jealousy. Parents also described siblings' feelings of sympathy in a variant category. One mother noted that "It seemed as if [sibling] was sad and she said to me one day, 'Why did this happen to our family?' She does not want to see her brother like this."

Discussion

This qualitative study used multiple perspectives to examine Latino siblings' experiences of living with a child with a developmental disability. Latino siblings and parents gave similar accounts of siblings seeking information about the child's disability. Both reported that siblings typically engaged in positive and negative interactions and caregiving with the child. Parent and sibling agreement about siblings' experiences suggested open communication and congruence between family members, both of which have been associated with better family adaptation to disability (Pit-Ten Cate & Loots, 2000; Snell & Rosen, 1997).

Parents and siblings diverged in their views of the negative impact of the child's disability. Parents described siblings as receiving differential treatment because of the child's disability. Not having enough time to attend to well siblings was salient for mothers who had the primary childcare responsibilities. Their concerns were consistent with existing literature on siblings' experiences of the child with special needs receiving more parental attention (Foster et al., 2001).

Siblings described restricted opportunities to participate in social activities because of their brother/sister. Being with peers may be more salient for Latino siblings growing up in the United States where children spend more time in extra-curricular and peer group activities than with their families (Fuligni, Tseng, & Lam, 1999).

Siblings described positive and negative interactions with their brother/sister, indicating commonalities in the experiences of Latino and European-American siblings. In contrast to previous sibling interview studies, the child's need for caregiving was a prominent topic in

the Latino sibling and parent narratives. Siblings were actively involved in helping and supervising the child and they appeared to be integral parts of each other's lives, consistent with Latino cultures where sibling relationships are given more importance and sibling caregiving is routine (Updegraff et al., 2005).

Unlike parents in previous interview studies, Latino parents in this study generally did not avoid discussing the disability. They talked with siblings about the child's problems. Their explanations included reasons for siblings to understand and to take care of their brother/sister. This parenting practice of giving siblings explicit messages about caregiving responsibilities suggested the process of socializing siblings towards the familistic value of family support and obligations (Arnett, 1995). The siblings' advice to others in a similar situation to take care of their brother/sister echoed their parents' words, implying that they have learned and internalized these values.

Most likely, a combination of factors contributed to high expectations for sibling caregiving including cultural values, child characteristics, and family resources. All of the children in this sample had developmental delays and required assistance for daily activities. Most families were lower income and 40% were single-parent homes. Lack of resources may have made it necessary for siblings to take on more responsibilities, since lower socio-economic status has been associated with increased sibling responsibilities in families with children with disabilities (Damiani, 1999).

Although siblings expressed negative feelings about their caregiving experiences, they also reported positive feelings about helping their brother/sister. A wider range of feelings was identified in sibling interviews than in parent interviews. Not surprisingly, siblings provided more information about their subjective emotional experiences which underscored the importance of obtaining first person accounts from multiple informants.

There were limitations in the current study. The families were from different Latino subgroups and although all children had developmental delays, they had different primary diagnoses. Therefore, experiences related to specific cultural subgroups and to unique aspects of a child's disorder may have been missed. The siblings' ages ranged from middle childhood to adolescence which limited our ability to discern issues related to their developmental stages. Although the interviews were scheduled at the family's convenience, only one father participated. Researchers should work towards increasing fathers' participation in future interview studies.

The sample size was consistent with the recommended number of participants for CQR analysis (Hill et al., 2005). However, information about eligible families who declined to participate in the study was not documented. Our sample may not be fully representative of the target population. Although we tried to account for our biases and expectations, personal viewpoints may have influenced analyses of the data. Given the paucity of research with this population, further qualitative and quantitative studies should be conducted with Latino families and investigations should be expanded by assessing variables such as family's immigration status and endorsement of cultural values.

Culture influences how individuals understand and cope with disability in the family. More research on families from diverse backgrounds is needed in order to develop culturally relevant and appropriate support services (Banks, 2003). There is a call for increasing ethnic minority groups' access to health information and services (Holliday, Dawes, Al-Mohamed, & Figueroa-Garcia, 2009). In our sample, all siblings reported talking to their parents about the child's problems. In addition to ensuring that Latino parents receive information about their child's disability, medical and educational professionals can assist them with providing developmentally appropriate explanations about the disability to siblings.

This qualitative study provided preliminary information about Latino siblings' experiences to a child's disability. Including parent and sibling perspectives revealed perceptions and expectations that may reflect Latino cultural values and highlighted the importance of considering siblings in sociocultural context.

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Key Messages

- More research on families from ethnic minority populations is needed to explore the role of culture in siblings' adjustment to disability in the family.
- Multiple family members should be included when examining sibling adaptation to a brother/sister's developmental disability.
- Qualitative research allows participants to describe their subjective experiences of family interactions, relationships, and the impact of a child's disability.

Table 1**Sibling Interview Domains, Categories, Frequency, and Examples**

Domain/Category	Frequency	Example
1. Sibling communication about the child's disability		
Wants information about the disability	Typical	"Sometimes I might ask her a question like why [child] was born like this."
Talks about child's condition	Typical	"I would to talk to [mother] about what problems [child] has at school and what time she has to wake up and everything."
Talks about child's negative behaviors	Variant	"Whenever [child] hits me, I always have to talk to Mom."
2. Sibling-child relationships		
Positive experiences	Typical	"I play with him. I read to him. Watch movies with [child]."
Negative experiences	Typical	"He's always bothering me, never lets me do my homework."
Caregiving experiences	Typical	"I help my mother take care of my brother. I tell him what to do, watch him, I supervise him."
3. Sibling-peer relationships		
Restricted social activities	Typical	"I don't get to be with my friends because I have to look after my sister."
4. Sibling positive feelings		
Re: sibling relationship	Typical	"Special to be an older sister."
Re: caregiving	Typical	"Sort of feels good 'cause I'm helping out."
5. Sibling negative feelings		
Re: sibling-child interactions	Variant	"Cause he might embarrass me in front of my friends. He gets on my nerves."
Re: restricted social activities	Variant	"Kind of mad if I can't go out or play with my friends."
Re: caregiving	Variant	"Sometimes it bothers me, I have to stop what I want to do, gets me mad."
Sadness/sympathy for the child	Variant	"Gets me sad that he has that problem."

Table 2**Parent Interview Domains, Categories, Frequency, and Examples**

Domain/Category	Frequency	Examples
1. Parent-sibling communication about the child's disability		
Etiology of the child's disability	Variant	"I tell [sibling], you know that [child] is like that, she was born like this."
Child's prognosis	Variant	"Like when [sibling] asks me if her sister will be like this for the rest of her life".
2. Parent explanations to siblings about the child's disability		
Understanding of the disability	Typical	"[Sibling] says why can't my little brother play with me. I tell him he needs more medical attention and lots of therapy so he can do what you do."
Understanding of caregiving responsibilities	Variant	"We always try to help him [child], always. For example, if he can't read something...There I had to explain to her [sibling] and there she really helps him in this type of thing."
3. Parent perspective on sibling relationships		
Positive interactions with child	Typical	"They get along. [Sibling] says, 'Mommy I love her a lot'."
Negative interactions with child	Typical	"I always have to be between them because [child] likes to hit [sibling]."
Sibling caregiving	Typical	"[Sibling] helps him, protects him, he likes protecting his brother, taking care of him."
Sibling differential treatment experiences	Typical	"Sometimes by giving [child] so much attention he [sibling] gets annoyed and he feels bad and he tells us 'you only love my little brother'."
4. Parent perspective on siblings' feelings		
Sibling negative feelings towards child	Typical	"[Sibling] sometimes gets mad and says because of [child] I can't go out and play because there is nobody to accompany me."
Sibling sympathy for child	Variant	"[Sibling] always says he feels sad and sorry for [child]."