

Sibling relationships in a global context: Findings from a survey of siblings of Special Olympics
athletes

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Abstract

Background

Research with siblings of those intellectual disabilities outside the Western cultural context is underrepresented in the literature. The aim of this study was to pilot a survey for siblings of Special Olympics athletes living in the Global South to understand their sibling relationship and community attitudes.

Method

Seventy-six siblings of Special Olympics athletes completed a survey that included questions about feelings towards, and interactions with, their sibling with intellectual disability, perceptions of their own social-emotional skills, and community attitudes towards disability.

Results

Participants reported more positive feelings towards their sibling with intellectual disability, strengths in their social abilities, but challenges with knowing their own strengths and emotions. Siblings also reported negative community attitudes towards intellectual disability.

Conclusions

The positive relationships reported by siblings are consistent with the larger literature base but challenges have implications for practitioners seeking to provide sibling support. Findings regarding community attitudes suggest negative attitudes as the primary impediment to inclusion for those with intellectual disabilities.

Sibling relationships in a global context: Findings from a pilot survey of siblings of Special Olympics athletes

Background

Within the family system, the sibling relationship is often the longest relationship in the lives of persons with and without intellectual disabilities (Cicirelli 1980; Noller 2005) and research has suggested mixed experiences across the life course. One on hand, having a sibling with intellectual disabilities promotes positive social-emotional skills such as patience, supportiveness, compassion, empathy, successful coping skills, and a better understanding of disability and diversity (Lee et al. 2021). Alongside these positive experiences of having a sibling with intellectual disability, there may also be feelings of anxiety, guilt, embarrassment, and isolation (Opperman & Alant 2003; Barr & McLeod 2010). These experiences are also influenced by one's cultural context which influences an individual's perceptions, understanding, and experiences (Lauderdale-Littin & Blacher 2017).

Research on sibling relationships for individuals with intellectual disabilities has largely taken place within the dominant Western culture leaving little understanding of how other cultural contexts influence the sibling relationship in similar or different ways (Hodapp et al. 2010). Culture influences family caregiving expectations, understanding of disability, and access to services and supports (Leigh, Hagiwara, & Black, 2021). Without taking these cultural differences into account, a full understanding of the sibling relationship is incomplete. Framing research on sibling relationships through a bioecological lens (Saxena & Adamsons 2013) allows for a fuller understanding of how cultural beliefs and practices may influence experiences of siblings of individuals with intellectual disabilities. Given the diversity of the world and

increasing diversity even within western culture, understanding cultural influences on sibling relationships is especially important.

Across cultures and ethnicities research has suggested that cultural context can have a significant impact on the experience of siblings without an intellectual disability (Lobato et al. 2011; Sage & Jegatheesen 2010; Tsai, Cebula, & Fletcher-Watson, 2016). The limited studies from non-Western cultural contexts suggest similarities in the experience of having siblings of individuals with intellectual disabilities including both positive and challenging experiences (Bhattashali et al. 2018; Tsai et al. 2018; Hansen et al. 2016; Mophosho et al. 2009; Paul et al., 2022). However, the content of these experiences may differ from non-Western cultural contexts. For example, some research has suggested that siblings of individuals with intellectual disabilities may not receive adequate knowledge about their sibling's disability due to fewer open conversations within the family system and more stigma surrounding disability (Bhattashali et al. 2018; Rana & Mishra 2015; Tsai et al. 2016). When communication between siblings and parents is characterized by less openness regarding intellectual disability siblings may have limited knowledge about intellectual disabilities and a reduced capacity to manage emotions (Bhattashali et al. 2018; Greeff & van der Walt 2010; Opperman & Alant 2003). Recent qualitative data from siblings of Special Olympics athletes in the Global South suggest a mix of both benefits and challenges related to having a sibling with a disability (Paul, et al., 2022). The benefits included feelings of pride and increased social emotional skills such as patience, acceptance, and maturity. Challenges included feelings of conflict around their own needs versus the needs of their sibling and the presence of stigma about disability among their community.

Cumulatively, these findings suggest that siblings from non-Western contexts experience largely similar positive impacts but may face unique challenges as compared to their non-

Western peers regarding knowledge about disability and community stigma. Our aim of this study was to pilot a survey of Special Olympics athletes to understand the sibling experience of having a brother or sister with intellectual disability in three key areas: perceptions of the sibling relationship, sibling social-emotional skills, and sibling perceptions of community attitudes towards intellectual disability.

Methods

Participants

Seventy-six siblings of individuals with intellectual disabilities participated in this study. All participants were siblings of Special Olympics athletes residing in three of the seven Special Olympics global regions who received funding to expand sibling and family outreach: Latin America, Africa, and Asia Pacific. Siblings were eligible to participate if 1) they were a sibling of a Special Olympics athlete and 2) were between the ages of 13 and 25. Parent consent was obtained for all participants younger than 18 years of age.

On average, participants were 21 years of age (range 13-25) and represented all three regions of the Global South, although representation from Africa (17%) was significantly lower than that of Asia Pacific (43%) and Latin America (40%). Fifty-seven percent of the sample was female, 52% of the sample included older siblings of individuals with ID, and 77% lived in the same household as their sibling. Siblings reported that their brother or sister with ID represented a range of diagnoses including Down syndrome, autism, cerebral palsy, and general developmental delay or intellectual disability.

Measures

Participants were invited to take part in a survey administered online via the Qualtrics Survey Software system (Qualtrics, Provo; UT). The questions included in this survey were drawn from findings identified through focus groups with siblings of Special Olympics athletes (Paul et al. 2022). The survey included 25 questions focused on topics including feelings towards their sibling with ID, sibling interactions, social-emotional skills, community attitudes towards disability, and peer relationships. Survey questions grouped by topic are included Table 1. To accommodate the different language used across the regions, the survey was available in three languages: English, Spanish, and French.

Perceptions of Sibling Relationship: Siblings were asked seven questions regarding their own perceptions of their relationship with their sibling. Questions were scored on a three-point scale where 1 = never, 2 = sometimes, and 3 = often. Of these seven questions, four were positive in nature (lucky, proud of sibling and self, supported) and three were negative in nature (embarrassed, frustrated, sad). Two variables were created by summing scores across positive and negative questions. Positive perceptions of the sibling relationship had a possible minimum score of four and a maximum score of 12. Negative perceptions had a possible minimum score of three and a maximum score of nine.

Social-Emotional Skills: Siblings were asked seven questions about how easy or difficult it was to manage certain social-emotional skills. These skills aligned with those identified through the framework developed by the Collaborative for Academic, Social, and Emotional Learning (CASEL, 2003) such as self-awareness, social-awareness, relationship skills, self-management, and responsible decision making. Questions were initially scored on a four-point scale where 1 = very difficult, 2 = difficult, 3 = easy, and 4 = very easy. For purposes of analysis, questions were

recoded into a dichotomous variable where 0 = difficult and very difficult and 1 = easy and very easy.

Community Attitudes towards Disability: To measure sibling perceptions of community acceptance and stigma, seven questions were included that focused on community understanding of, and beliefs about, disability. Each question was rated on a five-point Likert scale with answer options ranging from “totally disagree” to “totally agree”. Higher scores on each question indicated more agreement.

Data Analysis: Data was analyzed using the Statistical Package for the Social Sciences (SPSS) Version 26. Analyses were descriptive in nature. Independent samples t-tests and Chi-Square analysis were used to analyze differences by gender.

Results

Results of this study will be discussed in terms of impacts on the sibling (positive and negative feelings, social-emotional skills, and peers) and community acceptance and stigma. Due to small sample sizes within regions, data was combined across regions for the purpose of analysis. Across the full sample, participants reported overwhelmingly positive ($M=10.55$, $SD = 1.5$) feelings towards their sibling with ID and felt overwhelmingly lucky and proud because of their siblings. Participants reported few negative feelings ($M = 4.40$, $SD=1.16$) regarding their relationships with their sibling with ID. There were no statistically significant differences by gender.

For social-emotional skills, siblings reported strengths in their social abilities along with challenges with self-awareness and perseverance. For example, over 80% of siblings reported that learning from people with different opinions and knowing when someone needs help is easy.

However, approximately one-third of siblings reported that knowing their own strengths and the emotions they feel are difficult. Although not statistically significant, there were some differences by gender. Females were more likely than males to report higher levels of self-awareness as females reported that it was easier to know their strengths and the emotions they feel. Females also reported more difficulty than males in terms of learning from people with different opinions than them and getting through something even when they felt frustrated. Broadly, both males and females reported that getting along with classmates or co-workers and knowing what was right or wrong was easy for them.

When asked about their friends who do not have siblings with intellectual disabilities, 59% of participants reported that they chose friends who are accepting of people with intellectual disabilities and 69% also indicated that their friends include their sibling with intellectual disability when they spend time together. However, over a quarter of participants (27%) reported that their friends don't understand their relationship with their sibling. There were no differences by gender.

Siblings' perceptions of their communities' attitudes toward disability were more mixed. Fifty percent of participants reported that people in their community were embarrassed by intellectual disabilities and used hurtful words to describe people with intellectual disabilities. Additionally, 53% of siblings reported that people in their community think that resources should be spent on people with ID. Almost 80% of siblings disagreed that people in their community believe that intellectual disabilities can be spread from person to person and that intellectual disabilities come from bad parenting, respectively.

Conclusions

This study was an important step in exploring the sibling experience of Special Olympics athletes across three regions underrepresented in research on sibling relationships for people with intellectual disabilities. The overwhelmingly positive relationships reported by siblings in this study is consistent with findings from studies in other regional contexts (Aksoy & Bercin 2008; Burbridge & Minnes 2014). Previous research has found that siblings of those with intellectual disabilities report high levels of pride in their sibling and an ability to highlight their strengths (Carter et al. 2020). Most siblings in this study reported that learning from others who are different from them or knowing when others need help is easy, whereas a much smaller percentage found it easy to identify their own strengths. This suggests that siblings of those with intellectual disabilities may need targeted support to identify their specific needs. This is consistent with literature suggesting that siblings are more likely to focus on “other-oriented empathy” and can struggle with self-compassion (Leane, 2019; Leedham et al. 2020), as well as literature indicating that siblings of individuals with intellectual disabilities are more likely to describe wishes for their family than for themselves (Paul et al., 2022). This insight is important for practitioners seeking to implement support programs for siblings and suggests a need to incorporate more focus on helping siblings with self-awareness.

Findings regarding community attitudes align with literature indicating that stigma from community members and the responsibility to confront that stigma is a significant challenge in these parts of the world (Paul et al., 2022). Additionally, the high number of siblings who expressed choosing friends who would accept their sibling with intellectual disability and involve their sibling with intellectual disability in activities suggests that siblings can help to mediate social interaction and facilitate inclusion. Collectively, this suggests that it is not myths

and misconceptions about intellectual disability that is the primary impediment to inclusion, but rather persistent negative attitudes.

Limitations

This study was limited by a small sample size especially among the Africa region. This was likely due to pivot from in-person to virtual data collection because of the COVID-19 pandemic during the study period. More research is needed in each of these regions to be able to do deeper analysis of similarities and differences of sibling experiences across cultural contexts.

Table 1: Sibling Survey Questions by Topic

Positive Perceptions

Because of my relationship with my sibling, I feel:

- Lucky
- Proud of my sibling
- Proud of myself
- Supported by my sibling

Negative Perceptions

Because of my relationship with my sibling, I feel:

- Embarrassed
- Frustrated
- Sad

Social-Emotional Skills

Please rate how easy or difficult the following skills are for you:

- Knowing what my strengths are
- Knowing the emotions I feel
- Learning from people with different opinions than me
- Getting through something even when I feel frustrated
- Knowing what is right or wrong
- Getting along with my classmates or coworkers

Peer Relationships

Please rate your agreement with the following statements regarding your friends

- I choose friends who are accepting of people with intellectual disabilities
- My friends include my sibling when we hang out
- My friends don't understand my relationship with my sibling
- My friends view me as a responsible person

Community Attitudes

Please rate your agreement with the following statements. People in my community...

- Think that intellectual disabilities are something to be embarrassed of
 - Know a lot about intellectual disabilities
 - Say children with intellectual disabilities are "stupid," "crazy," or other hurtful words
 - Think that money and resources should be spent on people with intellectual disabilities
 - Believe that intellectual disabilities can be spread from person to person
 - Believe that intellectual disabilities are passed down through families
 - Think that intellectual disabilities come from bad parenting
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