



Siblings' Perspectives on Down Syndrome: Emotional, Family, and Caregiving Experiences in a Tertiary Pediatric Hospital



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BACKGROUND



Family dynamics are significantly influenced when one member has Down Syndrome (DS). While literature frequently focuses on parental experiences, siblings' perspective is often overlooked.

OBJECTIVE

Determine the overarching perception of the siblings of individuals with DS receiving clinical care at the Instituto Nacional de Pediatría (INP), specifically pedagogical engagement, caregiving dynamics, and their interpersonal relationships with parents and peers.

METHODS

A descriptive, cross-sectional, mixed-methods study was conducted at the INP in 2021 utilizing surveys with Likert scales and open-ended questions. 72 participants were stratified by developmental stage (children, adolescents, adults), siblings under 8 years were excluded, and 7 were omitted due to missing age data. Evaluated areas: affective dimensions, daily activities, responsibilities, and diagnosis knowledge. Data were analyzed using means/SD for quantitative variables and thematic content for qualitative insights.

RESULTS

GENDER DYNAMICS AND FAMILY IMPACT

Female siblings perceived higher parental neglect due to attention dedicated to the child with DS but active support remained high, with both groups thoroughly enjoying helping their sibling learn new things.

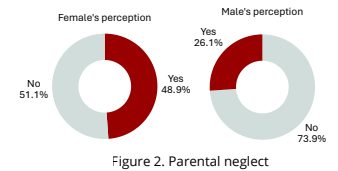


Figure 2. Parental neglect

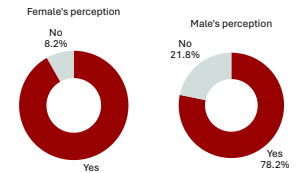


Figure 3. Enjoys helping sibling with DS learn

QUALITATIVE INSIGHTS: ADVICE TO PARENTS

Sibling responses fell into five categories, highlighting a collective commitment to fostering independence and strong refusal to overprotect.

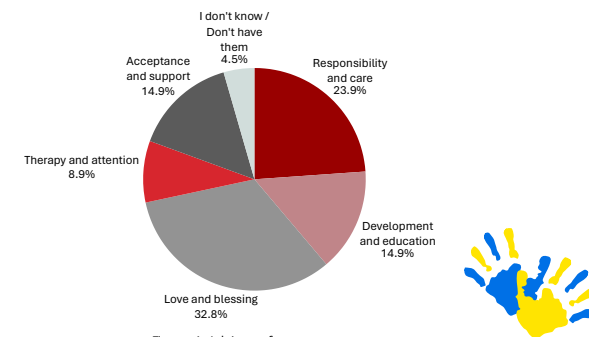


Figure 4. Advice to future parents

Demographic characteristic	Category	%
Gender	Female	68.0%
	Male	32.0%
Developmental Stage	Children (≤11 years)	31.9%
	Adolescents (12–19 years)	51.4%
	Adults (≥20 years)	6.9%
Household Closeness	Actively Cohabiting	85.8%
Family Structure	Small Nucleus (1–2 siblings)	83.0%

EMOTIONAL DIMENSIONS BY AGE-GROUP

Love and pride are universal (>91%); however, emotional focus shifts from childhood sadness over the diagnosis to adult sibling anxiety regarding social teasing and long-term support.

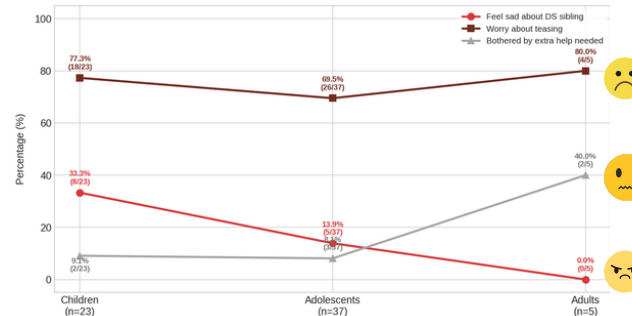


Figure 1. Negative or ambivalent feelings towards Siblings with DS.

CONCLUSIONS

While siblings of individuals with DS share universal bonds of love and pride, they navigate age-specific emotional nuances and gender-based disparities in parental attention. High prevalence of concern regarding social teasing underscores their deep resilience and empathy, marking an urgent need for societal awareness. Recognizing siblings as active stakeholders within family nucleus is fundamental to family-centered healthcare. Incorporating their unique perspective is essential to optimize comprehensive care strategies and significantly enhancing the quality of life for the entire family unit.

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