Family dynamics and psychosocial functioning in children with SCI/D from Colombia, South America

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Objective: The purpose of this study was to examine the connections between family dynamics and the psychosocial functioning of children with spinal cord injuries and disorders (SCI/D).

Design: Cross-sectional.

Setting: Participants were recruited from communities in Neiva, Colombia.

Participants: Thirty children with SCI/D and their primary caregiver participated. Children were between 8 and 17 years of age, and had sustained their injury at least six months prior to data collection.

Interventions: NA.

Outcome measures: Participating children completed measures assessing their own psychosocial functioning (Children's Depression Inventory, Revised Children's Manifest Anxiety Scale-2, Pediatric Quality of Life Inventory), and their primary caregiver completed measures of family dynamics (Family Adaptability and Cohesion Evaluation Scale- Fourth Edition, Family Communication Scale, Family Assessment Device-General Functioning, Family Satisfaction Scale, Relationship-Focused Coping Scale).

Results: A correlation matrix showed a number of significant bivariate correlations between child and family variables, and three multiple regressions showed that family satisfaction, empathy, and flexibility significantly explained 27% of the variance in child worry; family satisfaction and communication explained 18% of the variance in child social anxiety; and family cohesion and communication explained 23% of the variance in child emotional functioning.

Conclusions: These findings highlight the importance of rehabilitation professionals considering the association between family dynamics and the psychosocial functioning of children with SCI/D when working with this population.

Keywords: Emotional status, Family, Health-related quality of life, Pediatrics, Psychosocial factors, Spinal cord injuries, Spinal dysraphism

Introduction

The frequency of pediatric SCI is not known, though it is estimated that children 0–15 years make up about 4% of those newly injured,¹ with higher rates of SCI in developing countries due to high levels of violence and poverty.² The distribution of males and females who sustain an SCI before five years of age is approximately

equal, with an increasing percentage of males injured thereafter.^{3,4} A greater proportion of SCI in children and adolescents is accounted for by vehicular accidents, sports, violence, and medical complications than in adults, with a greater percentage of paraplegia and complete lesions in children injured before the age of 13.³ Neurological recovery, however, is thought to be better in children with SCI than in adults.⁵

Whereas SCI is an acquired impairment, spina bifida (SB) is a congenital defect of neural tube formation during gestational development in which one or more

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vertebrae are left open.⁶ The three types of SB include spina bifida occulta (the mildest form; does not involve damage to the spinal cord), meningocele (when the membrane which surrounds the spinal cord protrudes through the opening in the spinal column), and myelomeningocele (the most severe form, with spinal cord protrusion).⁷ A common comorbid condition of myelomeningocele is hydrocephalus (increased accumulation of cerebrospinal fluid in the brain), which can lead to increased intracranial pressure and produce cognitive deficits.^{8,9} In the United States the overall prevalence of SB among children is 3.1/10 000, with higher rates noted in Latino children (4.17/10 000).¹⁰ No accurate data exist on the prevalence of SB in Latin America, but recent nation-specific efforts to fortify wheat flour with folic acid have preliminarily shown effectiveness in reducing the occurrence of SB.¹¹

While pediatric SCI and SB vary in terms of their etiology, their physical and psychosocial sequelae have many commonalities. Both disorders can similarly impact child development in several domains, including physical (restriction of physical activities, multiple medications and surgical interventions, chronic pain, diminished strength and energy compared to peers),^{12,13} psychological (depression, anxiety, lower levels of self-esteem),^{14–16} and social (limited peer relations, deficits in social skills and judgment, social rejection)^{17–19} functioning. Therefore, the term ‘spinal cord injury and disorders’ (SCI/D) will be used for the purposes of this study to include both SCI and SB.

In addition to negative consequences of SCI/D on the physical and mental health of children with this disorder, families are often affected as well. According to the family systems/social-ecological perspective which, when used as a framework for the current study, provides a comprehensive view of family functioning in families affected by SCI/D, the child’s disability has an impact on all family members as well as the relationship between them.²⁰ Research findings support a ‘disruption-resilience’ view²¹ of the impact of SCI/D on family functioning, such that some aspects of family and parent functioning are disrupted in many families, but such families also tend to demonstrate resilience across other adjustment domains.²² More specifically, families with SCI/D may be less responsive to their child’s developmental and maturational changes,²³ tend to score within the clinically problematic range on measures of family functioning,¹⁴ exhibit lower family cohesion, lower mother-child agreement on measures of activity preference, and higher noise levels in the home environment than families of able-bodied children.²⁴ Further, these issues appear to be

exacerbated by lower socioeconomic status of SCI/D families.²⁴ No studies have examined the positive impacts of pediatric SCI/D on families, though some studies have found that resilience in families of adults with SCI/D is an important predictor of increased levels of positive affect, decreased levels of negative affect, and decreased caregiver burden.²⁵ Similarly, when compared to SCI/D families with lower resilience, families with higher resilience report certain caregiver management strategies as more helpful. Another study identified improvements in domain-specific functioning. Families of adults with SCI/D reported post-injury increases in family closeness and compassion, and decreased alcohol consumption.²⁶

Although research has shown pediatric SCI/D populations to experience poorer school, social, and emotional functioning, along with increased stress in the family system,^{12,18} very little research¹⁴ has examined the connections between the psychosocial functioning of children with SCI/D and family dynamics. No research has been conducted to date on either of these issues in Latin America. The purpose of the current study was to examine the associations between these two sets of characteristics in a sample of children with SCI/D and their caregivers from Colombia, Latin America. It was hypothesized that family functioning and child psychosocial functioning would be associated such that children with SCI/D who reported better psychosocial functioning would have caregivers who also reported better family functioning.

Methods

Participants

The current study included 30 children and their primary family caregiver, recruited from Hospital Universitario Hernando Moncaleano Perdomo in Neiva, Colombia. Children were included if they were between 8 and 17 years of age, were diagnosed with an SCI/D prior to the age of 17, and had sustained their injury at least six months prior to data collection. Children were excluded if, according to caregiver report, they had any diagnosis of a serious developmental disorder, psychiatric disorder, or any neurological condition in addition to the SCI/D. Medical records were additionally reviewed in order to exclude any potential participants who had previously sustained a traumatic brain injury. Each child’s family caregiver also participated. Participation criteria for caregivers required them to have been the primary family caregiver of the participating child for at least three months, and to have no self-reported history of serious psychiatric or neurological problems. See Table 1 for participant demographics.

Table 1 Participant Demographics and Scale Descriptives

Variables	Children, <i>n</i> = 30	Caregivers, <i>n</i> = 30
Age, years, mean (<i>SD</i>)	13.5 (2.9)	41.3 (11.0)
Sex, <i>n</i>		
Male	20	3
Female	10	27
Cause of injury/disorder, <i>n</i>		
Spinal cord injury	7	—
Myelomeningocele	22	—
Acute transverse myelitis	1	—
Socioeconomic status, mean (<i>SD</i>)	—	1.8 (0.7)
Family Dynamics, mean (<i>SD</i>)		
Pathology	—	2.10 (0.5)
Empathy	—	19.43 (7.7)
Cohesion	—	1.85 (0.7)
Flexibility	—	1.49 (0.5)
Communication	—	38.50 (8.0)
Family satisfaction	—	34.20 (6.6)
Child Psychosocial Functioning, mean (<i>SD</i>)		
Depression	12.0 (6.6)	—
Anxiety	17.2 (7.3)	—
Physical Functioning	50.0 (20.9)	—
Emotional Functioning	64.0 (20.1)	—
Social Functioning	68.2 (14.4)	—
School Functioning	59.0 (15.2)	—

Children were male ($N = 20$) and female ($N = 10$), with an average age of 13.5 years ($SD = 2.9$). Participant family socioeconomic status ranged from levels 1 to 4 ($M = 1.8$, $SD = 0.7$) as defined by the Colombian government with higher numbers reflecting greater income. A variety of SCI/D causes were identified including motorcycle crash ($N = 1$), car crash ($N = 1$), spinal cord atrophy ($N = 1$), falling into a river ($N = 1$), gunshot ($N = 3$), and acute transverse myelitis (CNS demyelination; $N = 1$), with the majority of children's injuries caused by Myelomeningocele (SB; $N = 22$). Caregivers were male ($N = 3$) and female ($N = 27$) with an average age of 41.3 years ($SD = 11.0$). Caregivers' relationship to the child with SCI/D included mother ($N = 20$), father ($N = 2$), aunt ($N = 1$), uncle ($N = 1$), grandmother ($N = 4$), and other ($N = 2$).

Measures: child

Children completed measures of their own mental health and health related quality of life (HRQOL), and caregiver participants completed measures of family dynamics. Child measures were chosen that have been shown to contain appropriate items for the age range in the current study (8–17 years). Both participants also provided demographic information.

Children's depression inventory (CDI)

The CDI is a 27-item assessment of depressive symptomatology.²⁷ Using this tool, children age 7–17 choose one

response from three options, that best describes their experience (e.g. I am sad once in a while, I am sad many times, I am sad all the time). Each response option corresponds with a numerical value ranging from 0 (absence or near absence of all symptoms) to 2 (severe symptoms). The CDI yields a total score of the summed responses, and scores of 20 or higher suggest clinically significant depressive symptomatology. The CDI has previously been applied to research in children with SCI.^{28,29} The current study employed the Spanish version of the CDI (CDI-LA) which has demonstrated adequate reliability ($\alpha = 0.87$) and validity.³⁰

Revised children's manifest anxiety scale-2 (RCMAS-2)

The RCMAS-2³¹ is one of the most widely used assessments of anxiety in children age 6–19 and has been used in research conducted in multiple languages and cultures.³² The RCMAS-2 yields four subscales (Physiological Anxiety, Worry, Social Anxiety, and Defensiveness) from 49 dichotomous-response (yes/no) items. The Defensiveness subscale is a measure of inconsistent responding and was therefore not used as an index of anxiety in the current study. The RCMAS-2 has been used in other studies of children with SCI,^{28,29} and subscale internal consistency ranges from 0.75 to 0.92.³¹

Pediatric quality of life inventory (PedsQL)

The PedsQL³³ is a modular, child self-report instrument that measures HRQOL across four subscale domains (Physical, Emotional, Social, and School Functioning) in children with chronic illnesses/disease conditions. Responders indicate the extent to which each of 24 items is problematic for them with options ranging from 0 (never a problem) to 4 (almost always a problem). A psychosocial health summary (sum of responses to emotional, social, and school functioning scales) and a physical health summary (physical health functioning scale) are derived from the 24 items. Each of the 24 items is reverse scored and linearly transformed into a 100 point scale. From the transformed items, scale scores are created (sum of items divided by the number of items completed). A score of 100 indicates the best possible health related quality of life. The current study used a Spanish translation of the measure that was created by the PedsQL authors. Previous research has used the PedsQL in children with SCI²⁹ and has demonstrated strong psychometric properties.³⁴

Measures: caregiver

Family adaptability and cohesion evaluation scale-fourth edition (FACES-IV)

The Spanish version of the FACES-IV was used to measure family cohesion and flexibility.³⁵ The FACES-IV yields two scale scores indexing these two constructs, and higher scores suggest greater cohesion and flexibility. The Spanish version of FACES-IV has demonstrated adequate concurrent, content, and convergent validity, and good internal consistency ($\alpha = 0.87$).³⁶

Family communication scale (FCS)

The FCS, a scale that is part of the FACES-IV package, was utilized to assess the quality of participants' family communication.³⁷ Respondents indicate their agreement on ten items with endorsement options ranging from 1 (strong disagreement) to 5 (strong agreement). Total scores range from 10 to 50, and higher scores suggest better family communication. A Spanish version³⁷ of the FCS was used in the current study, though it has not yet been validated. The English version of the FCS has demonstrated good temporal stability,³⁷ construct validity,³⁸ and internal consistency ($\alpha = 0.97$).³⁸

Family assessment device- general functioning (FAD-GF)

The FAD-GF is a 10-item measure of pathology in the family system.³⁹ Respondents endorse their degree of agreement with each item using a 4-point scale (strongly agree to strongly disagree). Response values are totaled for a total score, and higher scores suggest greater pathology in the family system. The FAD-GF has demonstrated good discriminant validity,³⁴ though no psychometric properties are available for the Spanish translation as it was created for the current study. The translation methodology suggested by Chapman and Carter⁴⁰ was utilized in this study for translation of the FAD-GF and all other measures translated for the purpose of this study. In line with Chapman and Carter's methodology, a bilingual and bicultural researcher translated the measures into Spanish, and a second bilingual and bicultural researcher translated the measures back to English. Any resulting discrepancies were addressed mutually.

Family satisfaction scale (FSS)

The FSS,³⁷ a scale that is part of the FACES-IV package, measures the extent to which respondents feel pleased and satisfied with their family's overall functioning and relationships. Total scores are the sum of responses to the scale's 10 items to which participants indicate their level of satisfaction from 1 (very dissatisfied) to 5 (extremely satisfied). Total scores range from

10 to 50 with higher scores indicating greater family satisfaction. The Spanish version of the FSS has shown excellent internal consistency ($\alpha = 0.92$)⁴¹ and good discriminant validity.³⁷

Relationship-focused coping scale (RFCS)

The RFCS is a measure of empathic responding within the family.⁴¹ Participants rate the frequency of their empathic response behaviors on 10 items using a 4-point response scale ranging from 0 (not at all) to 3 (a lot). Higher total scores represent greater empathic responding within the family system. The RFCS has been shown to have high internal consistency ($\alpha = 0.93$).⁴² The RFCS was translated for the current study.

Procedures

This study was approved by the ethics committee at the Universidad Surcolombiana, in Neiva, Colombia. Potential participants with SCI/D were identified through a review of medical records at the University of Neiva's Hospital Universitario Hernando Moncaleano Perdomo. The Hospital is a public teaching hospital that serves the people of Neiva. It is the only hospital in the city of Neiva, the capital of the Huila region, and offers physical medicine and rehabilitation services including speech therapy, occupational therapy, and physiotherapy. Individuals with SCI/D meeting the inclusion criteria were contacted via telephone, when researchers informed participants (caregivers and children) of participation expectations. If contacted individuals agreed to participation, a home visit was scheduled.

During the home visit, children with SCI/D and their caregivers completed informed consent/assent and participated in an interview conducted by a psychologist who was under supervision of a university psychology professor. While some of the measures administered to children with SCI/D were originally intended to be completed in paper-pencil style, in order to maintain the psychometric integrity of the study, all measures were administered verbally to child participants. This is because many children with SCI/D in Colombia may not have had school access and therefore may not have the ability to read and respond in written form to scale items. In many cases, parents or other family members were present when the children were interviewed; however, all caregiver participants completed their family dynamic measures independently of the children participants in writing.

Statistical analyses

A Pearson correlation matrix was calculated to examine the bivariate relations among child psychosocial

functioning variables and family dynamics variables. In order to maximize the power of the limited sample size in the current study ($n = 30$ dyads), the results of the correlation matrix informed later regression analyses. Because three child psychosocial functioning variables (worry, anxiety, and emotional functioning) were found to correlate significantly with at least one family dynamics variable, three regressions were conducted with each of these child psychosocial functioning variables as the dependent variable. These regressions were meant to allow an examination of which specific family dynamics aspects were most associated with specific indices of child psychosocial functioning. The independent variables in each regression were the family dynamics shown to correlate significantly with a particular child psychosocial functioning variable in the correlation matrix, and the dependent variable in each regression was each child psychosocial functioning variable shown to correlate with at least one family dynamics variable. Child psychosocial functioning variables included child depression (CDI), three RCMAS-2 subscales (physiological anxiety, worry, and social anxiety), and the four subscales of the PedsQL (physical, social, school, and emotional functioning). Family dynamics variables included pathology (FAD), empathy (RFCS), cohesion and flexibility (FACES-IV), communication (FCS), and satisfaction (FSS). An alpha level of 0.05 was used for all analyses.

Results

Scale distributions

The means and standard deviations for the family dynamics and child psychosocial functioning variables are presented in Table 1. The mean of the Relationship-Focused Coping Scale (RFCS) for this sample was higher than the mean of 1.64 ($SD = 0.64$)

in the scale's original construction,⁴¹ such that the current sample reported higher empathy than the normative sample. On the Family Adaptability and Cohesion Evaluation Scale—Fourth Edition (FACES-IV), the majority had cohesive families, and 73.3% were classified as flexible. On the Family Communication Scale (FCS), 56.7% of caregivers reported good family communication, and 23.3% reported low or very low communication. On the Family Satisfaction Scale (FSS), 53.3% of caregivers reported low or very low satisfaction, and 46.7% reported being satisfied. On the Family Assessment Device—General Functioning (FAD-GF), 76.7% of the sample was classified as having problematic family functioning.

In terms of child psychosocial functioning, 23.3% of children scored in the clinically significant range on the Children's Depression Inventory (CDI). The mean of the Revised Children's Manifest Anxiety Scale-2 (RCMAS-2) in the current study of 17.2 was higher than that reported in a previous study²⁸ of children with SCI (9.5), suggesting a high level of anxiety in the current sample. And finally, the subscale scores of the Pediatric Quality of Life Inventory (PedsQL) were generally comparable to the means found in a previous study of children with SCI in the United States.²⁹

Correlation matrix

Of all possible correlations between child psychosocial functioning and family dynamics variables, seven were significant (Table 2). Three family dynamics variables (empathy, flexibility, and satisfaction) were negatively correlated with child worry. Family satisfaction and child worry were the most strongly correlated variables in the matrix (-0.50). Child social anxiety was also negatively correlated with both family communication

Table 2 Correlations between family dynamics variables and child psychosocial functioning variables

Child Functioning	Family Characteristics					
	Pathology (FAD-GF)	Empathy (RFCS)	Cohesion (FACES-IV)	Flexibility (FACES-IV)	Communication (FCS)	Satisfaction (FSS)
Depression (CDI)	0.188	-0.067	-0.245	-0.209	-0.231	-0.198
Physiological Anxiety (RCMAS-2)	-0.033	-0.161	-0.095	-0.21	-0.074	0.008
Worry (RCMAS-2)	0.291	-0.366*	-0.256	-0.421*	-0.333	-0.496**
Social Anxiety (RCMAS-2)	0.198	-0.071	-0.266	-0.358	-0.368*	-0.398*
Physical Functioning (PedsQL)	-0.111	-0.3	0.079	0.103	0.161	0.238
Emotional Functioning (PedsQL)	-0.298	0.162	0.458*	0.216	0.384*	0.161
Social Functioning (PedsQL)	-0.113	-0.111	-0.173	-0.022	0.208	0.142
School Functioning (PedsQL)	-0.196	-0.04	-0.015	0.195	0.142	0.223

* $P < 0.05$; ** $P < 0.01$. CDI = Children's Depression Inventory; RCMAS = Revised Children's Manifest Anxiety Scale-2; PedsQL = Pediatric Quality of Life Inventory; FAD-GF = Family Assessment Device-General Functioning; RFCS = Relationship-Focused Coping Scale; FACES-IV = Family Adaptability and Cohesion Evaluation Scale-Fourth Edition; FCS = Family Communication Scale; FSS = Family Satisfaction Scale.

and satisfaction. Emotional functioning was the only positive correlate of family dynamics (cohesion and communication).

Regressions

The first regression examined the degree to which child worry was associated with family satisfaction, empathy, and flexibility. The three family dynamics variables explained 27% of the variance in child worry [$R^2 = 0.27$, $F(3, 29) = 3.23$, $P = 0.039$]. However, none of the family dynamics variables was independently associated with child worry within the overall model [all P s ≥ 0.226].

The second regression tested the degree to which child social anxiety was associated with family satisfaction and communication. These family dynamics explained 18% of the variance in child social anxiety [$R^2 = 0.18$, $F(2, 29) = 2.85$, $P = 0.075$], although the effect was marginally insignificant at the $P < 0.05$ significance level. Again, none of the family dynamics variables were independently associated with child social anxiety [all P s ≥ 0.269].

The final regression examined the degree to which child emotional functioning was associated with family cohesion and communication. These two family dynamics explained 23% of the variance in child emotional functioning [$R^2 = 0.23$, $F(2, 29) = 3.912$, $P = 0.032$]. None of the family dynamics variables were independently associated with child emotional functioning [all P s ≥ 0.113].

Discussion

The purpose of the current study was to examine the connections between family dynamics and the psychosocial functioning of children with SCI/D from Latin America. Previous studies of children with SCI/D have generally examined family functioning^{15,23,24} or child psychosocial adjustment¹⁵ independently, but very few have begun to look at the associations between these sets of constructs,^{14,39} and no formal studies have been published on this population in Latin America. Findings of this study, while preliminary in nature, lend further support to the 'disruption-resilience' view²¹ of the impact of SCI/D on family functioning. This theory posits that some aspects of family and parent functioning are disrupted in many families with SCI/D, but that these families also tend to demonstrate resilience across other adjustment domains.²² The current findings indicate that families with SCI/D demonstrate resilience with regard to their cohesion, communication, satisfaction, flexibility, and empathy. When these factors are present, they tend to be

associated with positive, resilient, responses from children (like decreased worry, increased emotional functioning, and decreased social anxiety).

Due to limited SCI/D research examining the relations between family dynamics and child psychosocial functioning, the findings of this first and preliminary study in this area can only be compared to existing research conducted with non-SCI/D populations. In the current study, caregivers' reports of family satisfaction, empathy, and flexibility were significantly associated with worry in children with SCI/D, with the regression reaching a large-sized effect. This finding is consistent with existing research on children without chronic health conditions that has shown child worry and anxiety to be associated with family environmental factors such as parenting style⁴³ and family functioning.⁴⁴ The finding that empathy is associated with child worry is an important one as it indicates that empathic family interactions may be associated with a child's adjustment to SCI/D, especially when combined with family flexibility. Accommodating a child with SCI/D in the family requires a great deal of adjustment and adaptation. If a family is able to adapt constructively and show empathy toward various members during that process, the child with SCI/D may worry less about his/her own health, or less worry in the child could also lead to an improvement in family dynamics.

Similarly, the finding in the current study that family satisfaction and communication were marginally associated with child social anxiety, potentially because of the study's limited sample size, reached a medium-sized marginally insignificant effect. This is consistent with previous research on non-SCI/D samples that has identified a relationship between family interpersonal conflict (poor communication) and increased child loneliness, which was related to social anxiety in that study.⁴⁵ Families with stronger communication patterns likely have children who feel more competent in social situations which might be associated with lower social anxiety they experience outside of the family.

Finally, the finding that family cohesion and communication were associated with child emotional functioning reached a medium-sized effect. This is consistent with research on other non-SCI/D pediatric populations showing that family functioning and child emotional functioning are closely associated.⁴⁶⁻⁴⁸ In the current study, families who are able to unite in the face of the challenges of having a child with SCI/D, and possibly do so through active and effective communication, are likely to have children with better emotional functioning. Children belonging to cohesive

and communicative families may also have better emotional functioning and are better able to communicate their needs and concerns to their family members.

Clinical implications

While the findings of this study are preliminary in nature, they begin to show that family functioning is associated with worry, social anxiety, and emotional functioning in children with SCI/D. These findings indicate that rehabilitation services for this population may be improved with interventions targeting increased satisfaction, empathy, flexibility, and communication within the family. This finding is particularly important given that familism is a central value to many individuals in Latin America which emphasizes the importance of family in one's life, especially when a family member has a health condition and other family members feel obligated to support and assist that person.^{49–51} The findings of this study suggest that family dynamics are associated with the psychosocial functioning and adjustment of children with SCI/D. As a result, family-systems interventions aimed at improving the various family dynamics identified in this study, as relating to child functioning, could coincide with child adjustment as well.

Limitations and future directions

There are several limitations of this study and as a result, directions for future research. First, only 30 participant/caregiver dyads were included due to challenges identifying and recruiting children with SCI/D and their caregivers in Neiva. Reduced statistical power limited the types of analyses that could be run on the data, such as more sophisticated modeling approaches, and even with the current analyses, small statistical effects present in the data could have gone unobserved. For example, the second regression on child anxiety was only marginally insignificant, where a larger sample size may have yielded statistical significance. Future research would benefit from a greater number of participants and could accomplish this by recruiting across multiple countries or rehabilitation facilities in Latin America. This would also increase the generalizability of the findings beyond Neiva, Colombia where the study was conducted.

Second, while sampling both children with SCI and SB in the same study increases the generalizability of findings to families/children with various spinal cord disorders, it also limits our understanding of the differences between these two samples whose medical conditions have distinct causes and subsequently perhaps distinct effects on families. Although the sample size

was too small in the current study, future research would benefit from considering differences between diagnostic populations with regard to family and child psychosocial variables. Consideration of these differences, if any, would increase our understanding of the mechanisms by which child psychosocial functioning is associated with family dynamics.

Similarly, while the current study is generalizable to children/families with various spinal cord disorders, the findings are limited in their generalizability to the population from which they were extracted. Participants in the current study largely were of low SES and were all living in Colombia. Because of these demographic characteristics, conclusions drawn from this study may be unique to this specific population. Further research should utilize similar methodologies in different populations so that findings can be more broadly generalized. Similarly, the specific dialects of the Spanish in the various scales used in this study may or may not have been fully culturally sensitive for the study's Colombian participants, so future studies would benefit from using scales that were first piloted for language and understanding in this population.

Also, while the current study considered a number of participant characteristics, some were not included, but should be considered in future research. For example, the current study did not collect data pertaining to the education level or literacy abilities of participating children or families. Because many people in Colombia lack access to higher education, this access may directly affect the resources that families of a child with SCI/D have, although this effect awaits investigation in future research. The inclusion of these characteristics would also allow future research to generalize better to other populations with similar economic or social resources.

Finally, in the current study, all identified relationships could be bidirectional or unidirectional in either direction. Family satisfaction, empathy, flexibility, and communication could influence the worry, social anxiety, or emotional functioning of a child with SCI/D, or child psychosocial functioning could influence family dynamics. As no longitudinal research was uncovered in the current literature review on family functioning and adjustment in children with SCI/D, further research should examine these variables longitudinally and construct cross-lagged panel designs to establish causality in this relationship so that interventions can better target the cause of problems of children with SCI/D and their families. This would have clinical implications for the current population, as family-systems interventions could improve family dynamics and therefore improve child psychosocial functioning,

or individual-level interventions to improve child psychosocial functioning could improve family dynamics, perhaps through the alleviation of caregiver burden.

Conclusion

Very few studies have investigated the associations between the psychosocial functioning of children with SCI/D and family dynamics, and none have done so in Latin America. The current study found that these sets of factors were related and suggest that research on rehabilitation interventions for children with SCI/D would benefit from a focus on improved satisfaction, communication, empathy, and flexibility in their families. If improvements to these aspects of family functioning using family-systems interventions are found to coincide with child psychosocial functioning as well, they could become an important part of rehabilitation for a population that to date has largely been neglected in the research literature.

Disclaimer statements

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References

- Nobunaga A, Go B, Karunas R. Recent demographic and injury trends in people served by the model spinal cord injury care systems. *Arch Phys Med Rehabil* 1999;80(11):1372–82.
- Henao-Lema C, Perez-Parra J. Lesiones medulares y discapacidad: revision bibliográfica [Spinal cord injury and disability: literature review]. *Aquichan* 2010;10(2):157–72.
- DeVivo M, Vogel L. Epidemiology of spinal cord injury in children and adolescents. *J Spinal Cord Med* 2004;27(Suppl 1):S4–10.
- Vogel L, DeVivo M. Etiology and demographics. In: Betz RR, Mulcahey MJ, editors. *The child with a spinal cord injury*. Rosemont, IL: American Academy of Orthopaedic Surgeons; 1996. pp. 3–12.
- Parent S, Mac-Thiong J, Roy-Beaudry M, Sosa J, Labelle H. Spinal cord injury in the pediatric population: a systematic review of the literature. *J Neurotrauma* 2011;28(8):1515–24.
- McLone D, Ito J. An introduction to spina bifida. Chicago: Children's Memorial Spina Bifida Team; 1998.
- Lemire R. Neural tube defects. *JAMA* 1988;259(4):558–62.
- Del Bigio M. Neuropathological changes caused by hydrocephalus. *Acta Neuropathol* 1993;85(6):573–85.
- Oppenheimer S. What is spina bifida?. In: Lutkenhoff M, editor. *Children with spina bifida: a parent's guide*. 2nd ed. Washington, DC: American Psychological Association; 2008. p. 2–10.
- Parker S, Mai C, Canfield M, Rickard R, Wang Y, Meyer R, et al. Updated national birth prevalence estimates for selected birth defects in the United States, 2004–2006. *Birth Defects Res A Clin Mol Teratol* 2010;88(12):1008–16.
- Castilla EE, Orioli IM, Lopez-Camelo JS, Dutra Mda G, Nazer-Herrera J, Latin American Collaborative Study of Congenital Malformations (ECLAMC). Preliminary data on changes in neural tube defect prevalence rates after folic acid fortification in South America. *Am J Med Genet A* 2003;123(2):123–8.
- Capute A, Accardo P. Developmental disabilities in infancy and childhood. Baltimore: Brookes; 1996.
- Warschawsky S, Engel L, Kewman D, Nelson V. Psychosocial factors in rehabilitation of a child with a spinal cord injury. In: Betz RR, Mulcahey MJ, editors. *The child with a spinal cord injury*. Rosemont, IL: American Academy of Orthopaedic Surgeons; 1996. p. 471–82.
- Ammerman R, Kane V, Slomka G, Reigel D, Franzen M, Gadow K. Psychiatric symptomatology and family functioning in children and adolescents with spina bifida. *J Clin Psychol Med Settings* 1998;5(4):449–65.
- Holmbeck G, Devine K. Psychosocial and family functioning in spina bifida. *Dev Disabil Res Rev* 2010;16(1):40–6.
- Kellerman J, Zeltzer L, Ellenberg L, Dash J, Rigler D. Psychological effects of illness in adolescence. I. Anxiety, self-esteem, and perception of control. *J Pediatr* 1980;97(1):126–31.
- Falvo D. Medical and psychosocial aspects of chronic illness and disability. 2nd ed. Gaithersburg, MD: Aspen Publishers Inc; 1999.
- Campbell J, Bonnett C. Spinal cord injury in children. *Clinical Orthopaedics and Related Research* 1975;112:114–23.
- Warschawsky S, Kewman D, Bradley A, Dixon P. Pediatric neurological conditions. In: Roberts M, editor. *Handbook of Pediatric Psychology*. 3rd ed. New York: Guilford Press; 2003. p. 375–91.
- Kazak A. Families of chronically ill children: A systems and social ecological model of adaptation and challenge. *J Consult Clin Psychol* 1989;57(1):25–30.
- Costigan C, Floyd F, Harter K, McClintock J. Family process and adaptation to children with mental retardation: disruption and resilience in family problem-solving interactions. *J Fam Psychol* 1997;11(4):515–29.
- Holmbeck G, Ariksson-Schmidt A, Bellin M, Betz C, Devine K. A family perspective: how this product can inform and empower families of youth with spina bifida. *Pediatr Clin North Am* 2010; 57(4):919–34.
- Coakley R, Holmbeck G, Friedman D, Greenley R, Thill A. A longitudinal study of pubertal timing, parent-child conflict, and cohesion in families of young adolescents with spina bifida. *J Pediatr Psychol* 2002;27(5):461–73.
- Holmbeck G, Coakley R, Hommeyer J, Shapera W, Westhoven V. Observed and perceived dyadic and systematic functioning in families of preadolescents with spina bifida. *J Pediatr Psychol* 2002;27(2):177–89.
- Simpson G, Jones K. How important is resilience among family members supporting relatives with traumatic brain injury or spinal cord injury?. *Clin Rehabil* 2013;27(4):367–77.
- McMillen JC, Cook CL. The positive by-products of spinal cord injury and their correlates. *Rehabil Psychol* 2003;48(2):77.
- Kovacs M. Rating scales to assess depression in school-aged children. *Acta Paedopsychiatr* 1981;56(5–6):305–15.
- Anderson CJ, Kelly EH, Klaas SJ, Russell H, Daharsh E, Vogel LC. Anxiety and depression in children and adolescents with spinal cord injuries. *Dev Med Child Neurol* 2009;51(10): 826–32.

- 29 Garma SI, Kelly EH, Daharsh EZ, Vogel LC. Health-related quality of life after pediatric spinal cord injury. *J Pediatr Psychol* 2011;36(2):226–36.
- 30 Davanzo P, Kerwin L, Nikore V, Esparza C, Forness S, Murrelle L. Spanish translation and reliability testing of the child depression inventory. *Child Psychiat Hum D* 2004;35(1):75–92.
- 31 Reynolds CF, Richmond BO. Revised children's manifest anxiety scale. 2nd ed. California: Western Psychological Services; 2008.
- 32 Reynolds S, Wilson C, Austin J, Hooper L. Effects of psychotherapy for anxiety in children and adolescents: a meta-analytic review. *Clin Psychol Rev* 2012;32(4):251–62.
- 33 Varni JW, Seid M, Rode CA. The PedsQL (TM): measurement model for the pediatric quality of life inventory. *Med Care* 1999; 37(2):126–39.
- 34 Varni JW, Seid M, Kurtin PS. PedsQL (TM) 4.0: reliability and validity of the pediatric quality of life inventory (TM) version 4.0 generic core scales in healthy and patient populations. *Med Care* 2001;39(8):800–12.
- 35 Olson D. FACES IV and the circumplex model: validation study. *J Marital Fam Ther* 2011;37(1):64–80.
- 36 Rivero N, Martínez-Pampliega A, Olson DH. Spanish adaptation of the FACES IV questionnaire: psychometric characteristics. *Fam J Alex Va* 2010;18(3):288–96.
- 37 Olson DH. FACES IV Manual. Minneapolis, MN: Life Innovations; 2010.
- 38 Thomas V, Lewis RA. Observational couple assessment: a cross-model comparison. *J Fam Ther* 1999;21(1):78–95.
- 39 Epstein NB, Baldwin LM, Bishop DS. The McMaster family assessment device. *J Marital Fam Ther* 1983;9(2):171–80.
- 40 Chapman DW, Carter JF. Translation procedures for the cross cultural use of measurement instruments. *Educ Eval Policy Anal* 1979;1(3):71–6.
- 41 Sanz M, Iraurgi I, Martínez-Pampliega A. Evaluación del funcionamiento familiar en toxicomanías: Adaptación española y características de adecuación métrica del FAP-FACES IV. In: Iraurgi I, González-Saiz F, editors. *Instrumentos de evaluación en drogodependencias*. Madrid: Aula Médica; 2002. p. 403–34.
- 42 O'Brien TB, DeLongis A. The interactional context of problem-, emotion-, and relationship-focused coping: the role of the big five personality factors. *J Pers* 1996;64(4):775–813.
- 43 Muris P, Meesters C, Merckelbach H, Hülsebeck P. Worry in children is related to perceived parental rearing and attachment. *Behav Res Ther* 2000;38(5):487–97.
- 44 Bögels SM, Brechman-Toussaint ML. Family issues in child anxiety: attachment, family functioning, parental rearing and beliefs. *Clin Psychol Rev* 2006;26(7):834–56.
- 45 Johnson HD, Lavoie JC, Mahoney M. Interparental conflict and family cohesion predictors of loneliness, social anxiety, and social avoidance in late adolescence. *J Adolescent Res* 2001; 16(3):304–18.
- 46 Brown RT, Lambert R. Family functioning and children's adjustment in the presence of a chronic illness: concordance between children with sickle cell disease and caretakers. *Fam Syst Health* 1999;17(2):165.
- 47 Carter AS, O'Donnell DA, Schultz RT, Scahill L, Leckman JF, Pauls DL. Social and emotional adjustment in children affected with Gilles de la Tourette's syndrome: associations with ADHD and family functioning. *J Child Psychol Psychiatry* 2000;41(2): 215–23.
- 48 Kashikar-Zuck S, Lynch AM, Slater S, Graham TB, Swain NF, Noll RB. Family factors, emotional functioning, and functional impairment in juvenile fibromyalgia syndrome. *Arthritis Care Res* 2008;59(10):1392–8.
- 49 Delgado M, Tennstedt SL. Puerto-Rican sons as primary caregivers of elderly parents. *Social Work* 1997;42(2):125–34.
- 50 Fuligni AJ, Tseng V, Lam M. Attitudes toward family obligations among American adolescents with Asian, Latin American, and European backgrounds. *Child Dev* 1999;70(4):1030–44.
- 51 Zsembik BA, Bonilla Z. Eldercare and the changing family in Puerto Rico. *J Fam Issues* 2000;21(5):652–74.
- 52 Boyer BA, Hitelman JS, Kolls ML, Kafkalas CM. Posttraumatic stress and family functioning in pediatric spinal cord injuries: moderation or mediation?. *Am J Fam Ther* 2003;31(1):23–37.