

# Parental Stress, Sense of Coherence, Marital Satisfaction, and Hope in Parents of Children with Spina Bifida

Fatima Arshad<sup>1</sup>, Humera Iqbal<sup>2</sup>, Waseem Akram<sup>3</sup> and Attiq Mumraiz<sup>4</sup>

<https://doi.org/10.62345/jads.2024.13.3.25>

## Abstract

*Spina bifida is an inborn abnormality that causes the spinal column to be split because the developing brain tube fails to shut during the fourth week of development. Caring for a child with Spina Bifida is a demanding and time-consuming responsibility that often requires parents to reassess their goals and priorities, leading to increased stress. As the implications of having a child with Spina Bifida on parents are varied and vast, the current study attempts to fill a gap in prior research by addressing the significance of the relationship between a sense of coherence, marital satisfaction, and the moderating role of hope. The current study was based on cross-sectional survey research. Data were collected with snowball sampling from parents with the age range between the ages of 25 years to 45 years from different hospitals located in Lahore and also online from social media groups. Findings revealed that parental stress is negatively related to marital satisfaction, and hope is positively associated with a sense of coherence. Hope also moderated the relationship between parental stress, sense of coherence, and marital satisfaction. The findings of this study will help to design social and moral support to facilitate such parents and enable them to face the challenges of parenting a child with SB.*

**Keywords:** Spina Bifida, Parental Stress, Sense of Coherence, Marital Satisfaction.

## Introduction

The birth of a child is a significant event in the lives of both parents since it introduces them to their parenting roles and responsibilities. Both parents modify and adjust themselves according to the necessities for their children's natural growth and physical needs (Barimani et al., 2017). Bringing up a child till they are self-sufficient is a difficult task for parents that requires substantial hard work as well as an assessment of their fortitude and competence (Nomaguchi & Milkie, 2020). However, bringing up a child with Spina Bifida is more difficult for the parents (Joseph, 2023). Spina bifida is a kind of disability that is considered one of the significant defects of a human structure that affects the central nervous system (Shlobin et al., 2022). It is an inborn abnormality that causes the spinal column to be split because the developing brain tube fails to shut during the fourth week of development. The vertebrae in the area of the damage are insufficient dorsally because of the absence of neural arches (Copp et al., 2015). Children with Spina Bifida typically require neurosurgery shortly after birth, and they face significant challenges, such as motor and tactile neurological impairments under the level of the lesion. Walking may become difficult or impossible as a result of lower limb weakness or paralysis, as well as a loss of feeling, increasing the risk of pressure sores, associated hydrocephalus, and learning impairments (Fletcher & Juranek, 2020).

<sup>1</sup>Clinical Psychologist, Ripah International University, Lahore. Email: [fatimaarshad173@gmail.com](mailto:fatimaarshad173@gmail.com)

<sup>2</sup>Clinical Psychologist, Email: [humera.iqbal08@gmail.com](mailto:humera.iqbal08@gmail.com)

<sup>3</sup>Counseling Psychologist, Ripah International University, Lahore. Email: [wasim510p@gmail.com](mailto:wasim510p@gmail.com)

<sup>4</sup>Clinical Psychologist, Email: [attiqakhan921@gmail.com](mailto:attiqakhan921@gmail.com)



The parents accounted for the unveiling of the diagnosis and understanding of Spina Bifida as an exceptionally torrid moment. This diagnosis shattered the dreams they had envisioned for their newborn baby. The diagnosis elicited emotions such as shock, denial, dread/nervousness, guilt, bitterness, vulnerability, and sadness among parents (Carroll & Carroll, 2023). Parents show concern for their child's future, whether or not they will be able to live an everyday independent life and fear the time when they are no longer there to care for them or when they will not be physically capable enough to look after their child's needs. Its diagnosis completely changes the family dynamics (Bujnowska et al., 2021). It redefines the role of both parents, increasing their responsibilities as parents, increasing the finances of the family, management of time among all the members of a family, social and professional responsibilities, and maintenance of their relationships along with their psychological well-being (Sacca et al., 2019).

The emotional well-being of parents is worsened by restricted resources, financial restraints, the lack of support groups, and the shortage of rehabilitation centers, which further intensify the negative effect of spina bifida. Over the last few decades, there has been a significant decrease in the prevalence of spina bifida globally (Ay et al., 2024). Nevertheless, in underdeveloped nations like Pakistan, the incidence of spina bifida continues to be high. Regrettably, we lack accurate statistics about the prevalence of spina bifida in Pakistan. The data indicates that the occurrence of neural tube abnormalities (NTDs) in Pakistan varies from 38.6 to 124.1 per 10,000 babies. This rate is significantly above the worldwide norm of 10 per 10,000 births. Pakistan, with its large population, is now grappling with a massive issue with Myelomeningocele (MMC) due to many factors. The reasons that contribute to this problem include a restricted availability of prenatal screening, a deficiency in the folate-fortified diet, the unavailability of folate supplements, and a high occurrence of consanguineous marriages (Khalil et al., 2023).

Caring for a child with Spina Bifida is challenging and time-consuming, forcing parents to reevaluate their goals and develop a sense of coherence as they adapt to shifting priorities, which contribute to heightened stress levels and further affect their psychosomatic well-being (Toledano-Toledano et al., 2020). An underexplored area in this context is the effect of caregiving on the quality of caregivers' marriages. While the importance of marital relationships has been studied in the general population and among caregivers of children with developmental disabilities (Jackson et al., 2014), little is known about its significance in families with children who have Spina Bifida. Marital relationships can play a crucial role in coping with the child's illness, as seen among mothers of mentally ill children who often rely on their husbands for support (Ghosh & Greenberg, 2012).

Another critical yet underexplored factor is the role of hope in moderating the effects of caregiving stress. Hope can provide parents with the resilience needed to face the overwhelming challenges of caring for a child with Spina Bifida, potentially alleviating stress and enhancing psychosomatic well-being. The unexplored role of hope as a moderating factor in the relationship between caregiving and marital satisfaction could be vital in understanding how families navigate the emotional and physical demands of their child's condition.

This study seeks to fill gaps in previous research by exploring factors related to parental stress in families with children who have Spina Bifida, including the impact of marital relationships and the moderating role of hope. There is a pressing need for greater societal awareness and understanding of this illness, as the financial and mental challenges faced by these families make caring for their children a constant source of concern. Incorporating hope into coping strategies could be instrumental in helping these families manage their stress and improve their overall well-being.

## Literature Review

### Parental Stress

Parental stress is characterized as the parental impression of an imbalance between the demands of child-rearing and accessible assets (Holly et al., 2019). Abidin (1995) categorizes parenting stress into three areas: stress due to the child's emotional and behavioral characteristics; stress related to parenting performance and psychological aspects such as feelings of shame, despair, and ineptitude in the parental role; and stress in the parent-child bond stemming from weak and adverse interactions, including conflicts and parental dissatisfaction with their relationship with their child and their role as a parent (Pinquart, 2017).

For parents of children with Spina Bifida, these stressors can be particularly pronounced. The child's health condition often brings significant emotional and behavioral challenges, amplifying parental stress (Holly et al., 2019). Additionally, the complex care demands and frequent medical appointments can exacerbate feelings of inadequacy and psychological distress in parents. Conflicts and strains in the parent-child relationship may also be heightened due to the ongoing care needs and associated stressors (Pinquart, 2017).

### Sense of Coherence

Humans have a sense of coherence related to their understanding of the world, their position in it, and their evaluation of life's situations as long as they are understandable, manageable, and meaningful. A crucial determinant for preserving health and well-being throughout challenging periods is the presence of a feeling of coherence (SOC). The salutogenic model, developed by Antonovsky, incorporates this notion as a fundamental component. The SOC includes the elements of comprehensibility, manageability, and meaningfulness and offers a framework that enables people to cope with trauma and adversity successfully (Nahal et al., 2022). Studies indicate that people with a strong sense of coherence are more adept at managing stress. They possess a wide array of coping skills and tactics, enabling them to adjust and choose the most efficient strategy for various circumstances (Einav & Margalit, 2020). Parenting a child with Spina Bifida is psychologically more challenging than parenting a child with typical development. A sense of coherence is a component that aids parents of children with Spina Bifida in successfully and efficiently responding to difficult situations, boosting their physical and emotional well-being while reducing stress (Shenaar-Golan, 2017).

### Marital Satisfaction

It can be characterized as a person's attitude toward his or her marital relationship. It is a holistic notion that encompasses many facets of married life, including adaptation, happiness, honesty, and commitment. The greater the stress generated by a marriage partner, the less content the individual is with the marriage and with the marriage partner in general (Sayehmiri et al., 2020). The strength of the marriage relationship has also been discovered to be a significant predictor of parenting experiences among parents of children with disabilities (Jackson et al., 2014). Satisfaction in a marital relationship is necessary for parents to provide support to each other to bear the burden of truly focusing on disabled children with variable changes. As a result, marital happiness is an essential factor in determining if a family is likely to have a problem when the entire family is expected to embrace the obligations involved with genuinely focusing on a child with a disability (Ekas et al., 2016).

### Hope

Hope is described as the seeming capacity to find paths to desirable outcomes and motivate oneself to choose those paths through agency thinking (Snyder, 2002). Existing research on family functioning in Spina Bifida families supports the relevance of hope in family functioning. That is, while having a child with Spina Bifida may disrupt family functioning

and lead some families to struggle, many families can adjust and display hope, idealism, optimism, and adaptation (Papadakis et al., 2018). When a child is diagnosed with Spina Bifida, the attitudes of parents and the availability of family financial resources change radically. Some parents experience distress and misery as a result of the loss of their dreams for their child and family, as well as an inability to adapt to the crisis (Rabba et al., 2019). In contrast, other parents gradually adapt to this ongoing challenge in their lives, resulting in increased hope, which ultimately increases their ability to adapt to stressful events (Kozachuk, 2022).

### **Theoretical Framework**

The Double ABCX model is a well-established framework for understanding family reactions to chronic child health issues, especially relevant for parents of children with Spina Bifida. The Double ABCX model explains how supplementary stressors may change the intensity of stress and the process of coordination among family behaviors during crises, termed "family adjustment and adaptation response" (McCubbin & Patterson, 1983). It is particularly applicable to caregivers of children with SB. It helps understand the interplay between stressors, coping resources, and family dynamics, shedding light on how a sense of coherence, marital satisfaction, and hope are influenced by the challenges of raising a child with Spina Bifida (Kozachuk, 2020).

### **Objectives of the Study**

The study was conducted to fulfill the following objectives.

- To study the relationship between parental stress, sense of coherence, marital satisfaction, and hope among the parents of children with Spina Bifida.
- To determine the impact of parental stress on the sense of coherence and marital satisfaction among the parents of children with Spina Bifida with the moderating role of hope.

### **Hypotheses**

To achieve the objectives of the study, the following hypotheses were formulated:

- Parental stress is likely to be negatively related to the sense of coherence in parents of children with Spina Bifida.
- Parental stress is likely to be negatively related to marital satisfaction in parents of children with Spina Bifida.
- Hope is likely to be positively related to the sense of coherence in parents of children with Spina Bifida.
- Hope is likely to be positively related to marital satisfaction in parents of children with Spina Bifida.
- Hope is likely to moderate the relationship between parental stress and a sense of coherence in parents of children with Spina Bifida.

### **Methodology**

The current study employed a quantitative, cross-sectional survey research design utilizing a snowball sampling approach. Data collection was conducted in both government and private hospitals in Lahore using self-report measures, i.e., the Parental Stress Scale (Berry & Jones, 1995), the Enriched Marital Satisfaction Scale (Fower & Olson, 1993), the Herth Hope Index (Herth, 1991), and the Orientation to Life Questionnaire (SOC-13 questions) (Antvosky, 1987). Participants were recruited from hospitals located in Lahore and through social media platforms. The sample consisted of 140 parents of children with Spina Bifida (SB), evenly divided between fathers and mothers. Participants ranged in age from 25 to 45 years ( $M = 35.31$ ,  $SD = 6.36$ ). In terms of education, 67% of the parents had completed 16 years of education, while the remaining 73% had 18 years of education.

Regarding family structure, 60% of the parents lived in a nuclear family system, while 80% resided in a joint family system. Notably, all 140 parents had only one child with SB, making this a unique aspect of the study's sample. Descriptive analysis revealed that 72% of the children with SB were girls. The children included in the study were aged between 1 and 12 years. Among them, 55% were between the ages of 1 and 4, which was the most frequent age group; 45% were between the ages of 5 and 8, and the remaining 40% were between 9 and 12 years old. The analysis also categorized the children according to the type of SB they were diagnosed with: 67% had Myelomeningocele, 12% had Meningocele, and 21% had Occulta. The researcher faced challenges in obtaining data from hospitals due to the limited number of neurologists and therapists treating SB. However, parents who participated in the study during their hospital visits for their child's treatment helped the researcher join social media communities for parents of children with SB. These online networks significantly facilitated the data collection process.

## Results

The Statistical Package for Social Sciences (IBM-SPSS Version 26) was used to evaluate data.

**Table 1: Pearson Correlation among Study Variables**

Variables	1	2	3	4
PSS	--	-.43**	-.38**	-.23*
SOC		--	.17*	.23**
MS			--	.44**
HHI				--

Note. PSS= Parental Stress Scale, SOC= Sense of Coherence, MS= Marital Satisfaction, HHI= Herth Hope Index

\* $p < .05$ , \*\* $p < .01$

The table shows the Pearson correlation among study variables. Results show that parental stress has a significant negative correlation with sense of coherence ( $r = -.43^{**}$ ,  $p < .01$ ), marital satisfaction ( $r = -.38^{**}$ ,  $p < .01$ ) and hope ( $r = -.23^*$ ,  $p < .01$ ). There is a substantial positive association between sense of coherence and marital satisfaction ( $r = .17^*$ ,  $p < .01$ ) and hope ( $r = .23^*$ ,  $p < .01$ ). The marital satisfaction has significant positive correlation with hope ( $r = .44^{**}$ ,  $p < .01$ ).

**Table 2: Moderation Analysis of Hope between Parental Stress and Marital Satisfaction (N=140)**

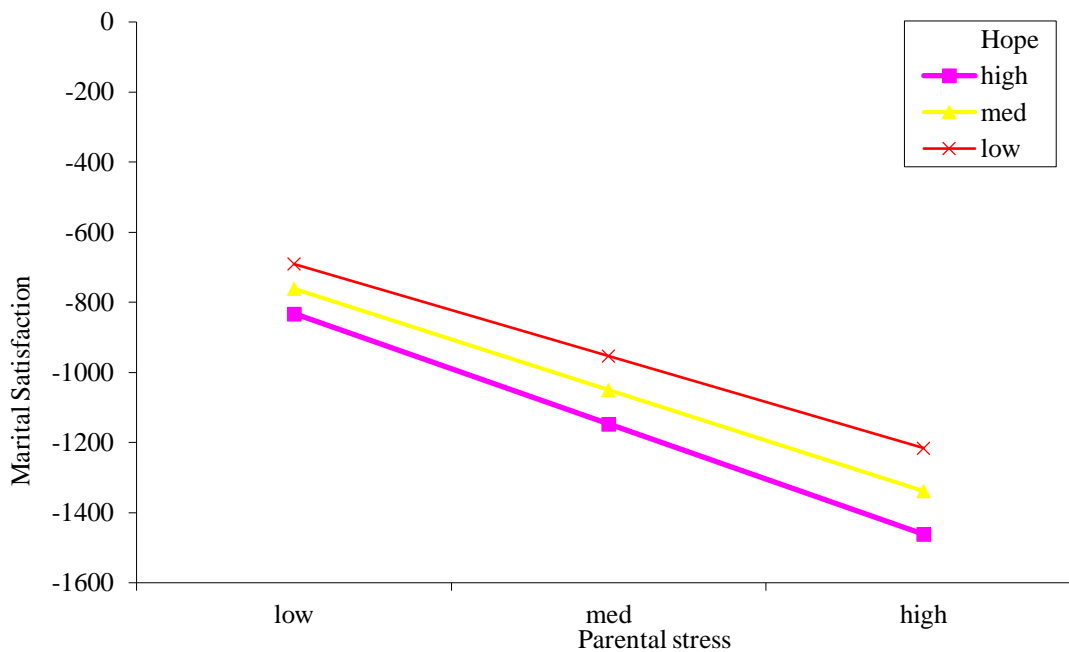
Variables	Model 1			Model 2		
	B	B	SE	B	$\beta$	SE
Constant	39.97***		1.38	37.91***		1.38
PSS	-5.64***	-.32***	1.39	-5.58***	-.32***	1.39
Hope	2.84**	.16**	1.39	3.08**	.17***	1.41
PSS $\times$ Hope				-1.30**	-.22**	1.50
$R^2$	.13			.14		
$\Delta R^2$				.01		

Note. PSS= Parental Stress

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

The table shows multiple regression analyses to moderate parental stress and marital enrichment. In model 1,  $R^2$  value of .13 indicates that the predictors explained 13% variance in the outcome with  $F(2, 137) = 10.87, p < .001$ . Results show that parental stress ( $\beta = -.32, p < .001$ ) and hope significantly predicted marital enrichment ( $\beta = .16, p < .001$ ). In model 2,  $R^2$  value of .14 indicates a 14% variance explained by hope in marital satisfaction with  $F(3, 136) = 7.84, p < .001$ . The  $\Delta R^2$  value of .01 revealed a 1% change in the variance of model 1 and model 2 with  $\Delta F(1, 137) = .74, p < .001$ . Results show that hope significantly moderated the relationship between parental stress and marital satisfaction ( $\beta = -.22, p < .01$ ).

**Figure 1: Moderation Analysis of Hope between Parental Stress and Marital Satisfaction**



The above figure shows that at a higher level of hope, the impact of parental stress decreases which increases the level of marital satisfaction.

**Table 5: Moderation Analysis of Hope between Parental Stress and Sense of Coherence (N=140)**

Variables	Model 1			Model 2		
	B	B	SE	B	$\beta$	SE
Constant	50.78***		1.02	50.73***		1.02
PSS	-4.92**	-.36**	.1.27	-4.88**	-.36**	1.03
Hope	2.94**	.22**	.1.27	3.10**	.23***	1.04
PSS $\times$ Hope				-.61	-.11***	1.11
$R^2$	.19			.20		
$\Delta R^2$				.01		

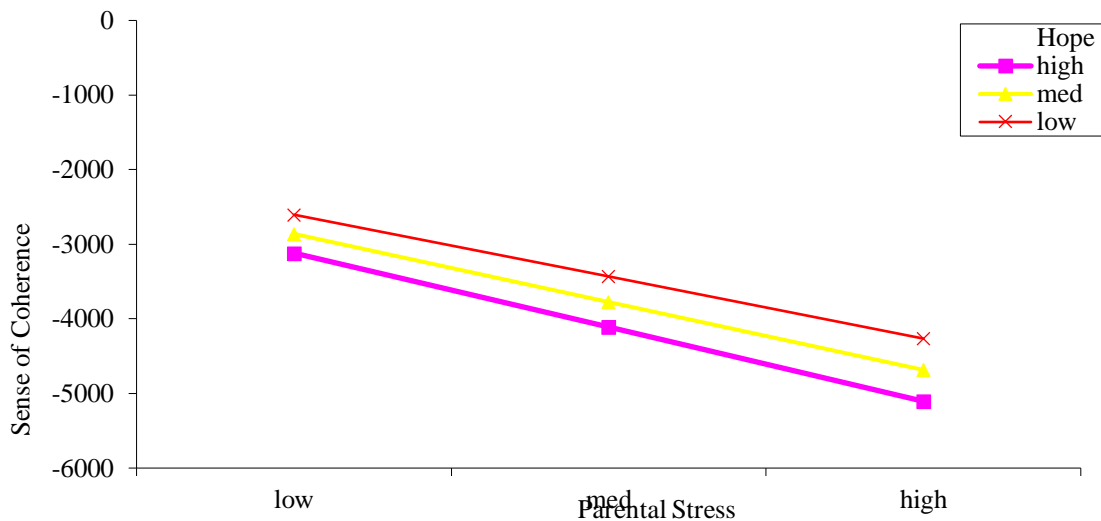
Note. PSS= Parental Stress

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$

The table shows multiple regression analyses to moderate parental stress and a sense of coherence. In model 1,  $R^2$  value of .19 indicates that the predictors explained 19 % variance in

the outcome with  $F(2, 137) = 16.34, p < .001$ . Results show that parental stress ( $\beta = -.36, p < .001$ ) and hope significantly predicted a sense of coherence ( $\beta = .22, p < .001$ ). In model 2,  $R^2$  value of .20 indicates a 20% variance explained by hope in the sense of coherence with  $F(3, 136) = 11.07, p < .001$ . The  $\Delta R^2$  value of .01 revealed a 1% change in the variance of model and model 2 with  $\Delta F(1, 137) = 5.99, p < .01$ . Results show that hope significantly moderated the relationship between parental stress and sense of coherence ( $\beta = -.11, p < .001$ ).

**Figure 2: Moderation Analysis of Hope between Parental Stress and Sense of Coherence**



The above figure shows that at a higher level of hope, the impact of parental stress decreases which increases the level of sense of coherence.

## Discussion

Living with a child with SB means dealing with the SB along with its challenges, demands, and overall impact on family and friends. The medical literature has several studies highlighting the impact of SB on persons who live with it, including emotional, social, and psychological issues (Kritikos et al., 2020). The impact on caregivers, on the other hand, has received less attention and is frequently disregarded. Care for someone with SB may be challenging owing to the disease's daily demands, which require medical advocacy and nursing, among other things (Rofail et al., 2012). The purpose of this study was to evaluate the association between parental stress and a feeling of coherence, as well as parental marital satisfaction and hope as a moderator.

The 1<sup>st</sup> hypothesis "parental stress negatively related to the sense of coherence and marital satisfaction among parents of children with Spina Bifida" was supported by findings. Due to the lack of understanding about Spina Bifida and their inability to care for a child with SB, inaccessibility to treatment and therapy brings forth stress levels among parents, which adversely affects their sense of coherence and their approach toward acceptance and adjustment. Results are supported by the previous literature by highlighting that the unmet requirements of children with SB are a continual source of stress and that parents suffer social hurdles in schooling and a lack of transportation due to financial constraints. An unknown developmental prognosis for these youngsters contributed to the parents' anxiety, even though they hoped their child would eventually marry and work (Nahal et al., 2022).

Batool and Khurshid, (2015) presents evidence for a link between parental stress and a sense of coherence. According to the findings, the amount of stress varies depending on one's assessment of the goal of their life (meaningfulness), accepting life's set of circumstances (comprehensibility), and their attitude and quantity of effort for the rearing of their child with SB (manageability). Parents with high-stress levels will have a poor sense of coherence; parents with a strong sense of coherence will have lower levels of stress. Literature also confirms that a good marital relationship, as assessed by both the person and the spouse, significantly moderates the negative consequences of many forms of distress (Rosand et al., 2012). Regarding marital satisfaction, parents with disabled children had a higher divorce rate; however, a few studies also found that this is not always the case (Marquis et al., 2019). A study conducted to explore the impact of a child's disability on families revealed that either there is a detrimental influence or no change in the marital relationships of parents. It shows that when spouses have a healthy marital relationship, dealing with a child's disability helps to strengthen their relationship and enrich their marital relationship further (Namkung et al., 2015).

Findings also found that hope is associated with a sense of coherence and marital happiness among parents of SB children. Hope has a considerable positive association with the feeling of coherence and marital satisfaction, according to the current data. Hope was the heart of art in the previous century, but in the last decade, hope has gotten major consideration as a study variable. According to literature, hope alters people's future and current perceptions of life and its challenges. Hope can reduce the unpleasant effects of difficult situations (Einav & Margalit, 2020).

## Conclusion

The current study highlighted the moderating impact of hope, as well as the association of parental stress with marital happiness and a feeling of coherence among parents of SB children. Raising a child with SB is a difficult task for parents, and it causes a lot of stress. The treatment of children with spinal bifida is made more difficult by the need for long-term and interdisciplinary follow-ups, as well as the need for different physiotherapy and rehabilitation programs. The findings of this research emphasize the specific factors that must be targeted in areas characterized by low socioeconomic status to mitigate the stress and burden faced by caregivers. Understanding the causes of stress necessitates an explanation for these observations. Being a parent to a child with SB changes their lifestyle, future goals, desires, beliefs, and knowledge of their parental obligations. To reduce the negative effects of spina bifida and ensure the children's social integration, modifying societal perceptions and beliefs about the child's condition is the first step in dealing with those effects. The outcomes of this study will contribute to a better understanding of both parents' experiences of raising a child with a disability. It will enable services to design social and moral support to facilitate such parents and enable them to face the challenges of parenting a child with SB.

## References

- Abidin, R. R. (1990). Parenting stress index. *PsycTESTS Dataset*. <https://doi.org/10.1037/t02445-000>
- Antonovsky, A. (1987). Health-promoting factors at work: The sense of coherence. Psychosocial factors at work and their relation to health. *Psychosocial Factors at Work and Their Relation to Health*, 153–167.
- Ay, L.A., Alataş, I., Özel, Ş.K. et al. (2024). Socioeconomic profile of families with spina bifida children in Turkey. *Egypt J Neurosurgery*, 39, 26 <https://doi.org/10.1186/s41984-024-00276-7>
- Barimani, M., Vikström, A., Rosander, M., Forslund Frykedal, K., & Berlin, A. (2017). Facilitating and inhibiting factors in the transition to parenthood – ways in which health professionals can



- support parents. *Scandinavian Journal of Caring Sciences*, 31(3), 537–546. <https://doi.org/10.1111/scs.12367>
- Batool, S. S., & Khurshid, S. (2015). Factors associated with stress among parents of children with autism. *Journal of the College of Physicians and Surgeons Pakistan*, 25(10), 752–756.
  - Berry, J. O., & Jones, W. H. (1995). Parental stress scale. *PsycTESTS Dataset*. <https://doi.org/10.1037/t02440-000>
  - Bueno-Pacheco, A., Satorres, E., Delhom, I., & Meléndez, J. C. (2021). Ego-integrity and its relationship with a sense of coherence, satisfaction, self-efficacy, and depression. *Current Psychology*, 42(8), 6439–6446. <https://doi.org/10.1007/s12144-021-01978-z>
  - Bujnowska, A. M., Rodríguez, C., García, T., Areces, D., & Marsh, N. V. (2021). Coping with stress in parents of children with developmental disabilities. *International Journal of Clinical and Health Psychology*, 21(3), 100254. <https://doi.org/10.1016/j.ijchp.2021.100254>
  - Copp, A. J., Adzick, N. S., Chitty, L. S., Fletcher, J. M., Holmbeck, G. N., & Shaw, G. M. (2015). Spina bifida. *Nature Reviews Disease Primers*, 1(1). <https://doi.org/10.1038/nrdp.2015.7>
  - Carroll, S., & Carroll, D. (2023). Spina bifida: Our story. *Journal of Pediatric Surgical Nursing*, 12(2), 46–49. <https://doi.org/10.1097/jps.0000000000000363>
  - Einav, M., & Margalit, M. (2020). Hope, loneliness and sense of coherence among bereaved parents. *International Journal of Environmental Research and Public Health*, 17(8), 2797. <https://doi.org/10.3390/ijerph17082797>
  - Ekas, N. V., Pruitt, M. M., & McKay, E. (2016). Hope, social relations, and depressive symptoms in mothers of children with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 29–30, 8–18. <https://doi.org/10.1016/j.rasd.2016.05.006>
  - Fowers, B. J., & Olson, D. H. (1993). Enrich marital satisfaction scale: A brief research and clinical tool. *Journal of Family Psychology*, 7(2), 176–185. <https://doi.org/10.1037//0893-3200.7.2.176>
  - Ghosh, S., & Greenberg, J. S. (2012). Gender difference in caregiving experience and the importance of social participation and marital satisfaction among aging mothers and fathers of adults with schizophrenia. *Social Work in Mental Health*, 10(2), 146–168. <https://doi.org/10.1080/15332985.2011.600637>
  - Herth, K. (1991). Development and refinement of an instrument to measure hope. . *Research and Theory for Nursing Practice*, 5(1), 39.
  - Holly, L. E., Fenley, A. R., Kritikos, T. K., Merson, R. A., Abidin, R. R., & Langer, D. A. (2019). Evidence-base update for parenting stress measures in clinical samples. *Journal of Clinical Child & Adolescent Psychology*, 48(5), 685–705. <https://doi.org/10.1080/15374416.2019.1639515>
  - Jackson, J. B., Miller, R. B., Oka, M., & Henry, R. G. (2014). Gender differences in marital satisfaction: A meta-analysis. *Journal of Marriage and Family*, 76(1), 105–129. <https://doi.org/10.1111/jomf.12077>
  - Joseph, R. (2023). Needs of parents of children with spina bifida. *Journal of Pediatric Surgical Nursing*, 12(1), 3–10. <https://doi.org/10.1097/jps.0000000000000360>
  - Khalil, M., Bakhshi, S.K., Shah, Z. et al. Quality of life in children operated for spina bifida; low- and middle-income country perspective. *Childs Nerv Syst* 39, 3155–3161 (2023). <https://doi.org/10.1007/s00381-023-05993-2>
  - Kozachuk, L. A., Wheeler, N. J., & Carr, S. (2022). The psychometric properties of the family relationship hope scale with parents and caregivers of children with autism spectrum disorder. *The Family Journal*, 30(4), 644–651. <https://doi.org/10.1177/10664807221104108>
  - Kritikos, T. K., Smith, K., & Holmbeck, G. N. (2020). Mental health guidelines for the care of people with spina bifida. . *Journal of Pediatric Rehabilitation Medicine*, 13(4), 525–534.
  - Marquis, S., Hayes, M. V., & McGrail, K. (2019). Factors affecting the health of caregivers of children who have an intellectual/developmental disability. *Journal of Policy and Practice in Intellectual Disabilities*, 16(3), 201–216. <https://doi.org/10.1111/jppi.12283>
  - McCubbin, H. I., & Patterson, J. M. (1983). The family stress process. *Marriage & Family Review*, 6(1–2), 7–37. [https://doi.org/10.1300/j002v06n01\\_02](https://doi.org/10.1300/j002v06n01_02)
  - Nahal, M. S., Wigert, H., Imam, A., & Axelsson, Å. B. (2022). Assessment of Health Status in adolescents with spina bifida in the West Bank, Palestine: Sense of coherence and self-perceived

- health. *Disability and Rehabilitation*, 44(19), 5479–5486. <https://doi.org/10.1080/09638288.2021.1936660>
- Namkung, E. H., Song, J., Greenberg, J. S., Mailick, M. R., & Floyd, F. J. (2015). The relative risk of divorce in parents of children with developmental disabilities: impacts of lifelong parenting. *American Journal on Intellectual and Developmental Disabilities*, 120(6), 514–526. <https://doi.org/10.1352/1944-7558-120.6.514>
  - Nomaguchi, K., & Milkie, M. A. (2020). Parenthood and well-being: A decade in Review. *Journal of Marriage and Family*, 82(1), 198–223. <https://doi.org/10.1111/jomf.12646>
  - Papadakis, J. L., Acevedo, L., Ramirez, S., Stern, A., Driscoll, C. F., & Holmbeck, G. N. (2017). Featured article: Psychosocial and family functioning among Latino youth with spina bifida. *Journal of Pediatric Psychology*, 43(2), 105–119. <https://doi.org/10.1093/jpepsy/jsx096>
  - Pinquart, M. (2017). Parenting stress in caregivers of children with chronic physical condition—a meta-analysis. *Stress and Health*, 34(2), 197–207. <https://doi.org/10.1002/smi.2780>
  - Rabba, A. S., Dissanayake, C., & Barbaro, J. (2019). Parents' experiences of an early autism diagnosis: Insights into their needs. *Research in Autism Spectrum Disorders*, 66, 101415. <https://doi.org/10.1016/j.rasd.2019.101415>
  - Rofail, D., Maguire, L., Heelis, R., Colligs, A., Lindemann, M., & Abetz, L. (2012). The impact of Spina bifida on caregivers. *Neurology and Therapy*, 1(1). <https://doi.org/10.1007/s40120-012-0004-8>
  - Saccà, A., Cavallini, F., & Cavallini, M. C. (2019). Parents of children with autism spectrum disorder: a systematic review. *Journal of Clinical & Developmental Psychology*, 1(3).
  - Sayehmiri, K., Kareem, K. I., Abdi, K., Dalvand, S., & Gheshlagh, R. G. (2020). The relationship between personality traits and marital satisfaction: A systematic review and meta-analysis. *BMC Psychology*, 8(1). <https://doi.org/10.1186/s40359-020-0383-z>
  - Shenaar-Golan, V. (2015). Hope and subjective well-being among parents of children with special needs. *Child & Family Social Work*, 22(1), 306–316. <https://doi.org/10.1111/cfs.12241>
  - Shlobin, N. A., Yerkes, E. B., Swaroop, V. T., Lam, S., McLone, D. G., & Bowman, R. M. (2022). Multidisciplinary Spina Bifida Clinic: The Chicago experience. *Child's Nervous System*, 38(9), 1675–1681. <https://doi.org/10.1007/s00381-022-05594-5>
  - Snyder, C. R. (2002). Target article: Hope theory: Rainbows in the mind. *Psychological Inquiry*, 13(4), 249–275. [https://doi.org/10.1207/s15327965pli1304\\_01](https://doi.org/10.1207/s15327965pli1304_01)
  - Toledano-Toledano, F., & Luna, D. (2020). The psychosocial profile of family caregivers of children with chronic diseases: A cross-sectional study. *BioPsychoSocial Medicine*, 14(1). <https://doi.org/10.1186/s13030-020-00201-y>