International Journal for Multidisciplinary Research (IJFMR)
E-ISSN: 2582-2160 ● Website: www.ijfmr.com ● Email: editor@ijfmr.com

Quality of Life and Motor Function in Children with Spina Bifida and Hydrocephalus: Impact on Family Functioning in Indian Rural Population

Jaspreet Singh Vij[1], Akanksha Nagar[2], Fatehjeet Singh Maan[3], Krishiv Mahajan[4], Abhilasha[5]

[1]Associate Professor, University College of Physiotherapy, Baba Farid University of Health Sciences, Faridkot (Punjab), India
[2]Research Assistant, Division of Neurology, Guru Gobind Singh Medical College and Hospital, Faridkot (Punjab), India
[3]Assistant Professor, State Institute of Nursing and Paramedical Sciences, Badal, Baba Farid University of Health Sciences, Faridkot (Punjab), India
[4]Student, Sat Paul Mittal School, Ludhiana (Punjab), India
[5]BPT Intern, University College of Physiotherapy, Baba Farid University of Health Sciences, Faridkot (Punjab), India

Abstract

Background & Purpose: Spina Bifida means "open spine", and refers to a common congenital birth defects involving a failure of the neural tube to close or to remain closed during early embryogenesis. A significant complication for infants born with myelomeningocele is the onset of hydrocephalus. In rural Indian populations, where socioeconomic constraints and healthcare accessibility are significant challenges, the correlation between motor function and QoL becomes a critical area of investigation. Thus, the purpose of this study is to explore quality of life and motor function in children with spina bifida and hydrocephalus… its impact on family functioning in Indian rural population.

Methodology: 20 Subjects with spina bifida and hydrocephalus, age 6 –10 years, both male and female with mean age of 47.30 months were assessed for their demographic profile according to selection criteria. They were assessed for quality of Life by using PedsQL Infant scoring Scale, Family functioning by using PEDSQLFIS, Motor function by using Gross Motor Function Measure (GMFM), socioeconomic status using Modified Kuppuswamy Socioeconomic Scale. The data was collected and computed in a systematic way and then analysed by using SPSS 20.

Results: Correlational analysis was done. Statistically significant correlation was found in duration of operation and GMFM, PedsQL Infant scoring Scale and GMFM.

Conclusion: This study shows that children with spina bifida and hydrocephalus in rural India benefit from better quality of life when they have improved motor skills. However, the impact of family dynamics, socioeconomic status, and the length of surgery on their quality of life was less clear. Overall, while good motor function is strongly linked to a better quality of life, other factors also play a role.

Keywords: Hydrocephalus, Family Impact, Motor Function, Spina Bifida, Quality of Life

Introduction:

Neural tube defects (NTDs) are severe birth defects of the central nervous system that originate during embryogenesis and result from failure of the morphogenetic process of neural tube closure.[1] It the second most common group of serious birth defects.[2] The incidence of myelomeningocele is highly variable and depends on ethnic, geographic and nutritional factors.[3]According to the data, low- and middle-income nations have a 20% higher birth prevalence of all birth abnormalities than do high-income nations.[4]The prevalence of NTDs is estimated to be between 0.5 and 1 per 1000 babies worldwide, with reports of variations ranging from 0.2 to 10 per 1000 newborns in particular geographic areas.[5] The overall prevalence of neural tube defects from India is high compared to other regions of the world. In India, the total number of births is 1000, and the pooled birth prevalence (random effect) for neural tube abnormalities is 4.5.[6] The most common birth defect in India is neural tube defects (NTDs).[7] India's reported frequency ranges from 0.5 to 11/1000 births, with the north of the country reporting a higher incidence than the south.[8,9] It was also found in various studies that myelomeningocele occurs most commonly among all NTDs and that too in the lumbar and sacral region.[10–13] A significant complication for infants born with myelomeningocele is the onset of hydrocephalus, characterized by the abnormal and progressive buildup of cerebrospinal fluid (CSF) in the brain's ventricles. Hydrocephalus is a leading cause of both morbidity and mortality in individuals with myelomeningocele. It affects individuals of all ages, with thousands of new cases each year in the United States and many more globally[14]. The incidence of congenital hydrocephalus has been estimated to be approximately 0.5 cases per 1,000 live births, while the overall incidence of neonatal hydrocephalus is estimated to be between 3 to 5 cases per 1,000 live births[15][16]. The prevalence of hydrocephalus is significantly higher in Africa and South America compared to other continents [17]. The estimated incidence of congenital hydrocephalus is highest in Africa and Latin America, with rates of 145 and 316 per 100,000 births, respectively, while the incidence is lowest in the United States/Canada at 68 per 100,000 births [17]. In Brazil, the prevalence of hydrocephalus is reported to be 0.374 per 100,000 inhabitants[18]. In India (Chhattisgarh), the male-to-female ratio for hydrocephalus cases was found to be 3:2. The highest incidence of infective hydrocephalus was observed in the 2 to 5 years age group, neoplastic hydrocephalus was most common in children aged 5 to 10 years, and congenital hydrocephalus was frequently reported in infants aged 1 to 6 months [19].

Lumbar meningomyelocele, which also has the potential to cause saddle anaesthesia, is frequently seen in cases of bladder or anal sphincter paralysis. The deformity results in numbness of the skin, paralysis of the legs, incontinence of urine and feces, and abnormalities of the feet, knees, and hips [20]. Patients with spina bifida are known to experience motor function impairment; their physical impairments include issues with posture and ambulation, as well as motor and sensory deficiencies. The degree of motor function correlates strongly with the amount of spinal injury; the more proximal the lesion, the lower the capacity to walk [21,22]

With a child's age and weight, the motor deficiencies usually get worse. The majority of patients with cervical and thoracic lesions do not live to adulthood, and wheelchair use is nearly universal among those with lesions at L2 and above [23]. Patients with lesions in the sacral level and lower lumbar (L5) usually have more motor strength and are able to walk till adulthood [23,24].

Spina bifida and hydrocephalus are complex congenital conditions that significantly impact the motor function and overall well-being of affected children. These conditions often result in various physical and cognitive disabilities, which can severely limit a child's ability to perform daily activities, thereby

influencing their quality of life (QoL). The effects extend beyond the individual child, placing immense emotional, financial, and psychological burdens on their families, particularly in rural settings where access to specialized care and support services is limited.

In rural Indian populations, where socioeconomic constraints and healthcare accessibility are significant challenges, the correlation between motor function and QoL becomes a critical area of investigation. This study aims to explore how the motor abilities of children with spina bifida and hydrocephalus relate to their QoL and that of their parents. Additionally, the study seeks to assess how social status influences QoL and examine the impact of the duration of surgical interventions on the overall well-being of both children and their caregivers. By identifying these correlations, the study hopes to inform targeted interventions that can enhance QoL outcomes for both children and families affected by these conditions in underserved rural communities.

Methodology:

This study employed an observational design with a correlational focus to explore the relationship between motor function, quality of life (QoL), and various other factors in children diagnosed with spina bifida and hydrocephalus. It was conducted at the Indoor and Outdoor Patient Departments of the Pediatrics Department at Guru Gobind Singh Medical College and Hospital, Faridkot, as well as the Outdoor Patient Department of Physiotherapy at the University College of Physiotherapy in Faridkot, Punjab. The research population consisted of children aged 6 months to 10 years, both male and female, who had been diagnosed with spina bifida and hydrocephalus. Ethical clearance was obtained from the Institutional Ethical Committee at Baba Farid University of Health Sciences, Faridkot, and informed written consent was secured from the parents or guardians of all participating children.

A total of 20 subjects were purposively selected, following screening of 28 potential subjects. The inclusion criteria required subjects to have been operated on for spina bifida and hydrocephalus, with a post-operative duration of 1 month to 3 years, and parents who understood Hindi. Exclusion criteria included any medical events interfering with testing outcomes, cognitive impairment, or other neurological disorders such as cerebral palsy. The subjects were enrolled in the study after fulfilment of inclusion and exclusion criteria. All the parents of subjects were explained the nature of study thoroughly and their informed consent on the behalf of their child was undertaken. each of the subjects was assessed for quality of Life by using Peds QL scoring Scale, family functioning by using PEDSQLFIS, motor function by using Gross Motor Function Measure (GMFM), socioeconomic status using by Modified Kuppuswamy Socioeconomic Scale and Mini Mental State Examination (MMSE) respectively each every above mentioned scales except Gross Motor Function Measure (GMFM) was used in Hindi version for the care of administration. All the scales were used with license obtained from respective sites. The scales were self-administrated by parents of the child with spina bifida and hydrocephalus. Any doubts or clarity on any question was explained by researcher during the administration. The total duration of administration consisted of 45 minutes. The GMFM scale was administrated by researcher and time taken was 20 minutes. Thus the final assessment taken and the scoring of each were done to calculate the total scores. The data collected and computed in a systematic way and then analysed by using SPSSv-20.

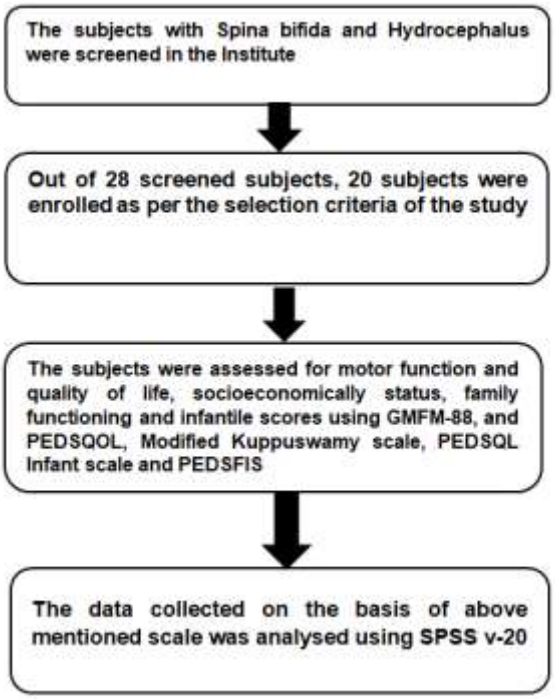

Figure 1: The flowchart of the study procedure

The Gross Motor Function Measure (GMFM) assesses motor capacity in children with cerebral palsy aged 5 months to 16 years, using a 4-point scale across 88 items in five dimensions: lying and rolling, sitting, crawling and kneeling, standing, and walking. Scores are based on the best of three trials per item and expressed as percentages of the maximum score for each dimension, with the total score being the average of these percentages. [25]

The Pediatric Quality of Life Inventory (PedsQL) Generic Core Scales assess pediatric health-related quality of life (HRQOL), capturing the impact of chronic diseases and treatments on a child's well-being [26]. The 15-item short form, derived from the original 23-item version, evaluates physical, emotional, social, and school functioning. [26] It includes both child self-report and parent proxy-report formats, with responses scored on a five-point scale and transformed to a 0–100 scale, where higher scores indicate better HRQOL. [26]

The Modified Kuppuswamy Socioeconomic Scale measures family socioeconomic status based on the head of the family's education, occupation, and total monthly income. It assigns scores from 1 to 7 for education, 1 to 10 for occupation, and 1 to 12 for income, with a total score ranging from 3 to 29. This scale requires regular updates to the income parameter to keep pace with inflation. [27]

The PedsQL™ Family Impact Module evaluates the impact of pediatric chronic conditions on family quality of life through 36 items across eight subscales. These subscales measure parents' physical, emotional, social, cognitive functioning, communication, worry, daily activities, and family relationships. Scores are based on a five-point Likert scale, with higher scores indicating better functioning and less negative impact. [28]

The PedsQL™ Infant Scales are designed to assess quality of life across different childhood age groups using both child self-report and parent proxy-report. They maintain consistency in content while adapting language for developmental differences. For instance, the scales use age-appropriate wording

for younger children and toddlers. This allows for accurate HRQOL evaluation across ages 2–18 years and supports longitudinal tracking of quality of life [26].

Results:

This study finding indicated that the mean age of the 20 subjects with spina bifida and hydrocephalus was 47.30 months, with a high variability in age. The gender distribution was nearly equal, with a mean of 0.65 for males and 0.35 for females. The average duration of operations was 136.15 days. The Gross Motor Function Measure (GMFM) scores averaged 78.25, while the PedsQL score averaged 82.39, and the Peds-FIS score averaged 122.57. The Kuppuswamy socioeconomic scale had a mean score of 11.00. The details are depicted in Table 1 and graphically represented in Figure 2,3.

In table 2, the correlation analysis revealed a strong, significant positive relationship between PedsQL and GMFM ($r = 0.793$, $p = 0.000$). However, correlations between PedsQL and Peds-FIS ($r = 0.166$, $p = 0.483$), GMFM and Peds-FIS ($r = 0.305$, $p = 0.191$), and between PedsQL and the Kuppuswamy scale ($r = 0.23$, $p = 0.33$) were weak or non-significant. The relationship between the duration of operation and PedsQL was moderate but not significant ($r = 0.324$, $p = 0.163$). In summary, significant correlations were observed only between PedsQL & GMFM and duration of operation & GMFM. The results are graphically represented in Figure 4-8.

Table 1: Description of Demographic Data of age, gender, duration of operation and scores of assessments.

S No.	Variables		N	Mean ± S.D	Range
1.	Age (in months)		20	47.30 ± 36.99	136
2	Gender	Male	13	0.65 ± 0.47	1
		Female	7	0.35 ± 0.47	1
3	Operation(in days)		20	136.15 ± 129.06	537
4	Scores of Gross motor function measure		20	78.25 ± 18.92	75
5	Scores of Pediatric Quality of life		20	82.38 ± 15.59	71.8
6	Scores of Pediatric Family Functioning Scale		20	122.56 ± 190.24	881.1
7	Scores of Modified Kuppuswamy scale		20	11.0 ± 2.44	11

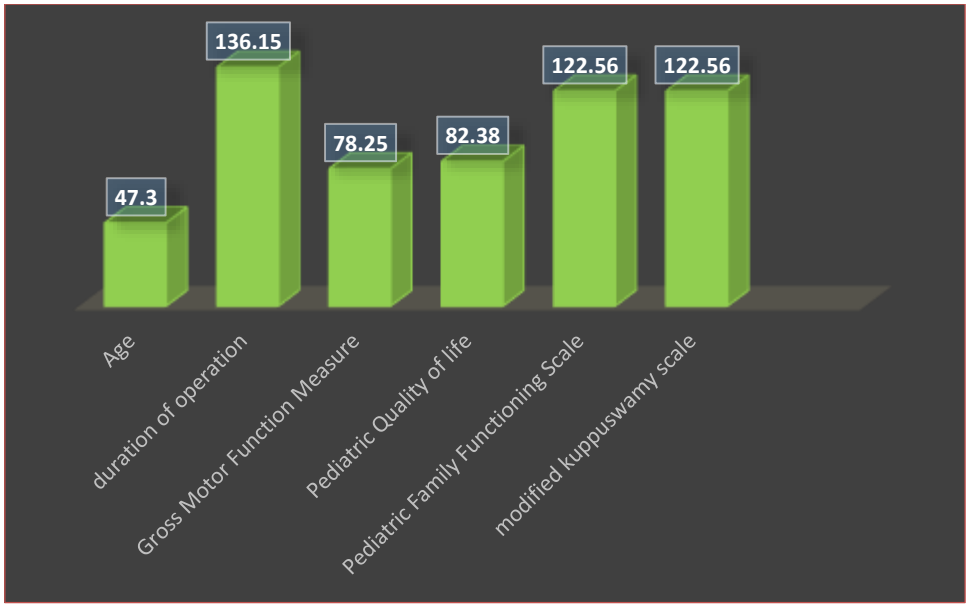

Figure 2: Graphical representation of Mean of Demographical data of subjects with Spina Bifida with Hydrocephalus

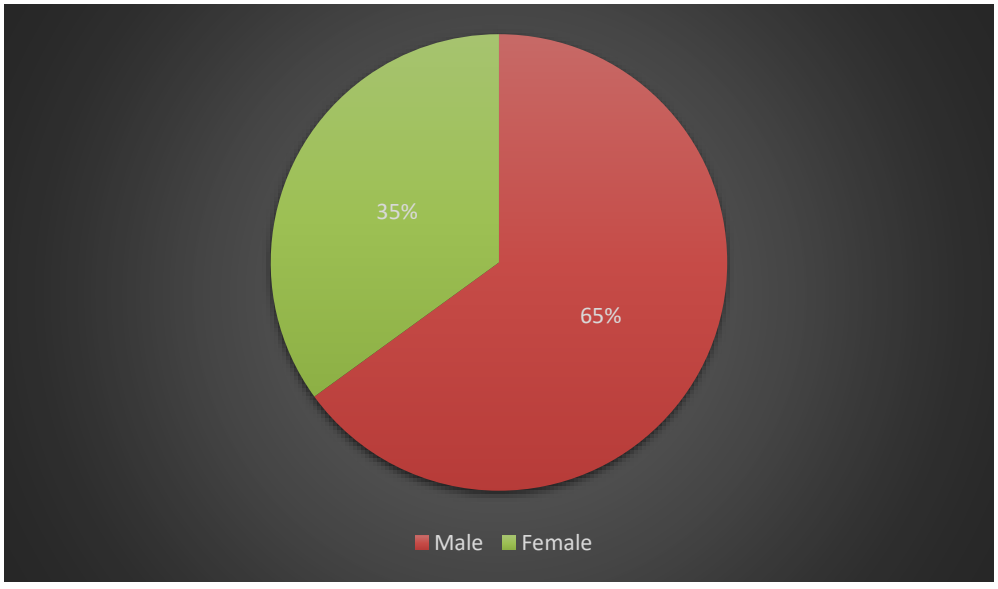

Figure 3: Gender Distribution of Subjects with Spina Bifida with Hydrocephalus.

Table 2: Description of Correlation Analysis between Variables.

S No.	Variables	r - value	p - value
1	Pediatric Quality of life & Gross Motor Function Measur	0.793	0.000 (S)
2	Pediatric Quality of life & Pediatric Family Functioning Scal	0.166	0.483 (NS)
3	Gross Motor function Measure & Pediatric Family Functioning Scale	0.305	0.191 (NS)
4	Modified Kuppuswamy scale & Pediatric Quality of life	0.23	0.330 (NS)

5	Duration of operation & Pediatric Quality of life	0.324	0.163 (NS)

S= Significant. NS= Non-Significant

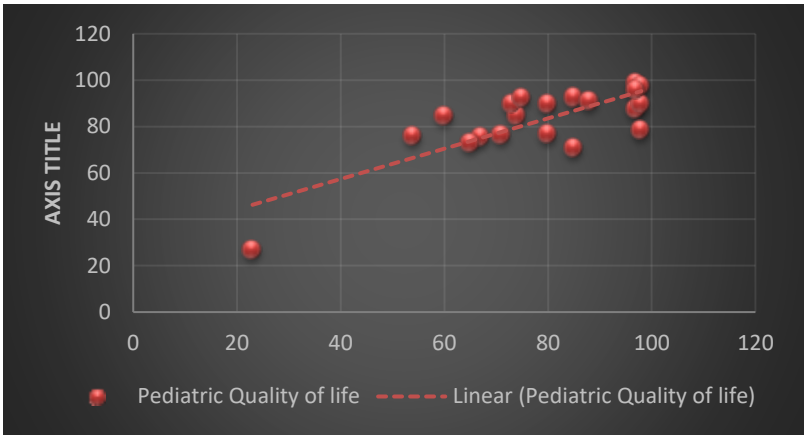

Figure 4: Graphical representation of Correlation between Scores of Pediatric Quality of life & Gross Motor function Measure.

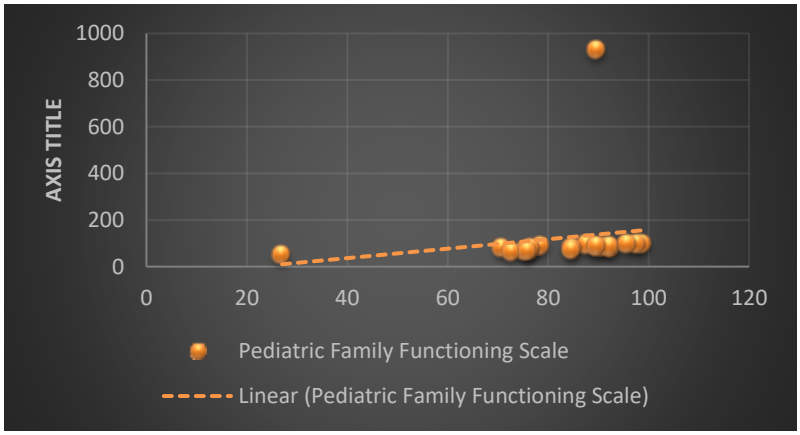

Figure 5: Graphical representation of Correlation between scores of Pediatric Quality of life & Pediatric Family Functioning Scale.

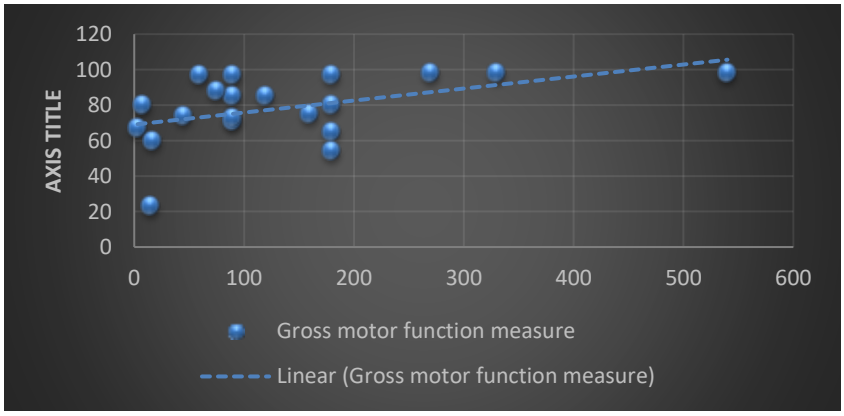

Figure 6: Graphical representation of Correlation between scores of Gross Motor function Measure & Pediatric Family Functioning Scale.

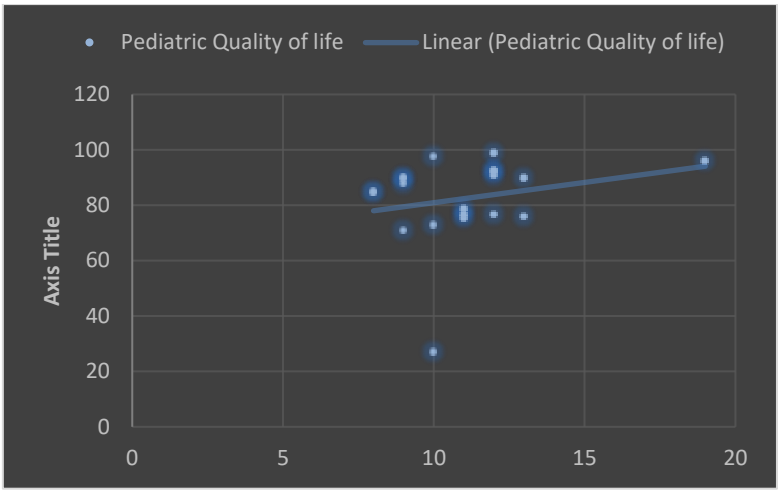

Figure 7: Graphical representation of Correlation between scores of Modified Kuppuswamy scale & Pediatric Quality of life.

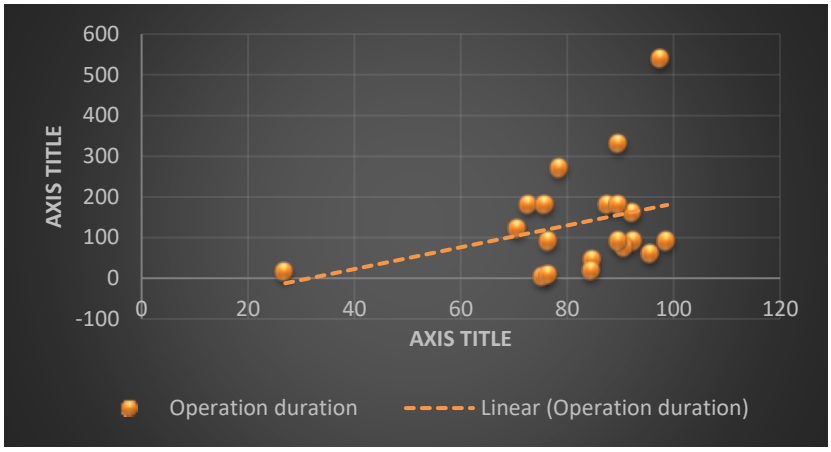

Figure 8: Graphical representation of Correlation between scores of Duration of operation & Pediatric Quality of life.

Discussion:

This study of total 20 subjects with mean age of 47.30 months represents a pioneering effort to explore the relationships between various factors affecting children with spina bifida, including Pediatric Quality of life & Gross Motor Function Measure, Pediatric Quality of life & Pediatric Family Functioning Scale, Gross Motor function Measure & Pediatric Family Functioning Scale, Modified Kuppuswamy scale & Pediatric Quality of life, Duration of operation & Gross Motor function Measure, Duration of operation & Pediatric Quality of life.

In spina bifida patients, quality of life (QoL) of infants scored by PedsQL Infant Scale reflected their overall well-being, including physical, psychological, and social aspects. [29] These patients often face mobility issues, medical challenges, and social isolation, affecting their health and participation in daily life. Gross motor function refers to their ability to perform large movements, which is often impaired due to neurological issues which is measured by Gross Motor Functional Measure [30]. This present study findings revealed a strong positive relationship between QoL and Gross Motor Function. The better gross motor function is linked to higher QoL in these children. The contributing factors include

increased independence, improved social participation, reduced physical discomfort, and fewer medical complications.

Family functioning, measured by the PedsQL Family Impact Scale, evaluates how a child's health condition affects family dynamics, including emotional well-being and daily activities. In the findings of the study, the weak positive relationship between Pediatric Quality of Life (QoL) and Family Functioning, indicated by an r-value of 0.166, suggested a mild association that is not statistically significant. This lack of significance could be due to varying family coping strategies, resources, and support systems. Some families may adapt effectively, leading to minimal impact on QoL, while others may experience greater challenges. Additionally, the focus on medical and physical care for spina bifida might overshadow the influence of family functioning on QoL [30,31]. External factors such as socioeconomic status, healthcare access, and individual resilience may also dilute the direct effect of family functioning on the child's QoL.

In this study, the relationship between GMFM and Pediatric Family Functioning, with a p-value of 0.191, suggested a weak and statistically non-significant association. This lack of significance might be due to several reasons. Firstly, improvements in gross motor function may not directly translate into noticeable changes in family functioning, as family dynamics are influenced by a broader range of factors beyond just motor abilities. Secondly, the scope of family functioning encompasses a variety of aspects that may not be directly affected by changes in motor skills, such as family stress, coping strategies, and support systems. Additionally, the impact of motor function on family life might be more nuanced and less immediate, leading to a weaker correlation. Finally, individual differences in family resilience and the specific nature of spina bifida's impact could further obscure the relationship between gross motor function and family dynamics [33].

The Modified Kuppuswamy Scale assesses socioeconomic status by evaluating factors such as education, occupation, and income. In this study, a score of 11.0 ± 2.44 on the scale typically places individuals in the lower-middle socioeconomic class. Pediatric Quality of Life (QoL) measures the overall well-being of a child, including physical, emotional, social, and educational aspects. The observed weak positive relationship between the Modified Kuppuswamy Scale score and Pediatric Quality of Life, suggested that socioeconomic status, as indicated by a lower-middle class classification, does not have a strong or statistically significant impact on the child's QoL [34]. Several factors could explain this lack of significance. Firstly, the impact of socioeconomic status on QoL might be moderated by other factors such as the child's health condition, family support systems, and access to healthcare. For example, children from lower-middle socioeconomic backgrounds might still receive high levels of emotional and practical support from their families, which could positively influence their QoL despite financial constraints. Secondly, the lower-middle class status might not fully capture the complexities of socioeconomic factors that impact QoL. Variables such as access to quality healthcare, educational resources, and social support can vary widely within this class, potentially diluting the direct effect of socioeconomic status on QoL. Lastly, the Modified Kuppuswamy Scale may not account for all nuances of socioeconomic status that could influence QoL. For instance, regional variations, cultural factors, and specific family circumstances might affect QoL independently of the broad socioeconomic category represented by the scale. This could lead to a weaker observed correlation between socioeconomic status and Pediatric Quality of Life.

The duration of an operation, in the current investigation averaged 136.15 days, and Pediatric Quality of Life (QoL), with an average score of 82.38, was examined to understand their relationship. The

correlation between the duration of the operation and QoL was found to be weak, with a non-significant p-value of 0.163. This suggests that the length of the surgical procedure does not have a strong or statistically significant impact on the child's quality of life. Several factors could contribute to this non-significant finding. First, the high average QoL scores observed in the study indicate that, despite variations in operation duration, children's overall well-being remains relatively high. This could mean that the length of the operation has a minimal effect compared to other aspects of their care and recovery. Additionally, individual differences in recovery, resilience, and support systems can influence QoL independently of the duration of surgery. The complexity of QoL involves multiple dimensions such as emotional, social, and psychological factors, which may overshadow the direct effect of operation duration. Moreover, the operational definition used in the study may not fully capture other critical aspects of surgical impact, such as the quality of the procedure or post-operative complications, which could play a more significant role in determining QoL. Thus, while the operation duration shows a mild positive association with QoL, it is not statistically significant, indicating that other factors are likely more influential in shaping the child's quality of life.

Several limitations in this study should be considered. The relatively small sample size of 20 subjects may limit the ability to detect significant effects and affect the generalizability of the results to a broader population. Additionally, the study's cross-sectional design captures data at a single point in time, which does not account for changes in the child's condition or family dynamics over time.

The study also did not account for variations in the severity of spina bifida among the subjects, which could influence the relationship between the variables studied. Individual differences in the extent of neurological impairment and associated complications may affect QoL, motor function, and family functioning, but these factors were not specifically analyzed.

Several limitations in this study should be considered. The relatively small sample size of 20 subjects may limit the ability to detect significant effects and affect the generalizability of the results to a broader population. Additionally, the study's cross-sectional design captures data at a single point in time, which does not account for changes in the child's condition or family dynamics over time. The study also did not account for variations in the severity of spina bifida among the subjects, which could influence the relationship between the variables studied. Individual differences in the extent of neurological impairment and associated complications may affect QoL, motor function, and family functioning, but these factors were not specifically analyzed.

While attempting to further expand this study, future research could explore several innovative avenues to further brings the understanding of the factors affecting children with spina bifida associated with hydrocephalus. Comparative studies across different regions or cultures could tailor interventions to specific needs, and targeted intervention research could test strategies to improve motor function, family support, and socioeconomic conditions. Additionally, integrating technological advancements, such as telehealth, into care strategies could offer innovative solutions for enhancing QoL.

Conclusion:

This study shows that children with spina bifida and hydrocephalus in rural India benefit from better quality of life when they have improved motor skills. However, the impact of family dynamics, socioeconomic status, and the length of surgery on their quality of life was less clear. Overall, while good motor function is strongly linked to a better quality of life, other factors also play a role. Future

research including longitudinal studies could provide insights into how changes over time in various factors impact QoL and new methods to better support these children and their families.

References:

1. Greene ND, Copp AJ. Neural tube defects. Annual review of neuroscience. 2014 Jul 8;37(1):221-42.
2. Yi Y, Lindemann M, Colligs A, Snowball C. Economic burden of neural tube defects and impact of prevention with folic acid: a literature review. European journal of pediatrics. 2011 Nov;170:1391-400.
3. Bowman RM, Boshnjaku V, McLone DG. The changing incidence of myelomeningocele and its impact on pediatric neurosurgery: a review from the Children's Memorial Hospital. Childs Nerv Syst . 2009 Jul ;25(7):801–6.
4. Christianson A, Howson CP, Modell B. March of Dimes: global report on birth defects, the hidden toll of dying and disabled children. 2005, xi-84
5. Zaganjor I, Sekkarie A, Tsang BL, Williams J, Razzaghi H, Mulinare J, et al. Describing the Prevalence of Neural Tube Defects Worldwide: A Systematic Literature Review. PLoS One. 2016 Apr 1;11(4):e0151586.
6. Allagh KP, Shamanna BR, Murthy GV, Ness AR, Doyle P, Neogi SB, Pant HB, Wellcome Trust-PHFI Folic Acid project team. Birth prevalence of neural tube defects and orofacial clefts in India: a systematic review and meta-analysis. PloS one. 2015 Mar 13;10(3):e0118961.
7. World Health Organization. Prevention and control of birth defects in South-East Asia Region: strategic framework (2013-2017). WHO Regional Office for South-East Asia; 2013.
8. Kavitha Sargunam DR. NUTRI-GENETIC DETERMINANTS OF NEURAL TUBE DEFECTS IN INDIA.
9. Verma IC. Burden of genetic disorders in India. The Indian Journal of Pediatrics. 2000 Dec;67:893-8.
10. Singh BK, Maria A, Bandyopadhyay T, Choudhary SK. Clinico epidemiological profile and outcomes of babies with neural tube defects in a tertiary care center in Northern India. The Journal of Maternal-Fetal & Neonatal Medicine. 2022 Dec 12 ;35(25):7052–7.
11. Premlal KV. A Retrospective Analysis of Clinical Profile and Surgical Outcome in Patients with Spinal Dysraphism at Tertiary Care Center. 2018 112 12.
12. Sidram V, Kumar PC, Raghavendra B, Sangreshi V. A Prospective Study of Spectrum of Spinal Dysraphisms and its Surgical Outcome. The Journal of Spinal Surgery . 2015 Sep ;2(3):72–7.
13. Kumar R, Singh SN. Spinal Dysraphism: Trends in Northern India. Pediatr Neurosurg . 2003 Mar 1 ;38(3):133–45.
14. Hochstetler A, Raskin J, Blazer-Yost BL. Hydrocephalus: historical analysis and considerations for treatment. Eur J Med Res. 2022 Sep 1;27(1):168.
15. Kahle KT, Kulkarni A V., Limbrick DD, Warf BC. Hydrocephalus in children. In: The Lancet. Lancet Publishing Group; 2016 Feb 20;387(10020);788–99.
16. Chi JH, Fullerton HJ, Gupta N. Time trends and demographics of deaths from congenital hydrocephalus in children in the United States: National Center for Health Statistics data, 1979 to 1998. J Neurosurg Pediatr. 2005 Aug;103(2):113–8.
17. Wiswell TE. Major Congenital Neurologic Malformations-Reply. American Journal of Diseases of Children. 1991 Jan 1;145(1):30.

18. Isaacs AM, Riva-Cambrin J, Yavin D, Hockley A, Pringsheim TM, Jette N, Lethebe BC, Lowerison M, Dronyk J, Hamilton MG. Age-specific global epidemiology of hydrocephalus:Systematic review, metanalysis and global birth surveillance. PloS one. 2018 Oct 1;13(10):e0204926.
19. 9. Dewan MC, Rattani A, Mekary R, Glancz LJ, Yunusa I, Baticulon RE, Fieggen G, Wellons JC, Park KB, Warf BC. Global hydrocephalus epidemiology and incidence: systematic review and meta-analysis. Journal of neurosurgery. 2018 Apr 27;130(4):1065-79.
20. 10. Dutra M, da Silva SC, Beggiora PD, Santos MV, Machado HR, Lopes LD. Epidemiology of hydrocephalus in Brazil. Jornal de pediatria. 2023 Jun 16;99:228-34.
21. 11. Jaiswal A, Jaiswal J. Incidence of hydrocephalus in pediatric age in a tertiary care centre of Chhattisgarh. Journal of Evolution of Medical and Dental Sciences. 2015 Oct 15;4(83):14564-72.
22. Ravi KS, Divasha, Hassan SB, Pasi R, Mittra S, Kumar R. Neural tube defects: Different types and brief review of neurulation process and its clinical implication. J Family Med Prim Care . 2021;10(12):4383.
23. Coniglio SJ, Anderson SM, Ferguson JE. Functional motor outcome in children with myelomeningocele: correlation with anatomic level on prenatal ultrasound. Dev Med Child Neurol . 1996;38(8):675–80.
24. Hirose S, Farmer DL, Albanese CT. Fetal surgery for myelomeningocele. Curr Opin Obstet Gynecol . 2001 ;13(2):215–22.
25. Harvey AR. The gross motor function measure (GMFM). Journal of physiotherapy. 2017 Jul 1; 63(3):187.
26. Varni JW, Seid M, Kurtin PS. PedsQL™ 4.0: Reliability and validity of the Pediatric Quality of Life Inventory™ Version 4.0 Generic Core Scales in healthy and patient populations. Medical care. 2001 Aug 1; 39(8):800-12.
27. Mohanty M, Patle RA, Narlawar UW. Modified BG Prasad and Modified Kuppuswami Socio-economic Status Scales: Revision and Updates for January 2024. Preventive Medicine: Research & Reviews. 2024 May 1; 1(3):166-7.
28. Scarpelli AC, Paiva SM, Pordeus IA, Varni JW, Viegas CM, Allison PJ. The Pediatric Quality of Life Inventory™ (PedsQL™) family impact module: reliability and validity of the Brazilian version. Health and Quality of Life Outcomes. 2008 Dec; 6:1-8.
29. Luz CL, Moura MC, Becker KK, Teixeira RA, Voos MC, Hasue RH. The relationship between motor function, cognition, independence and quality of life in myelomeningocele patients. Arquivos de Neuro-Psiquiatria. 2017 Aug;75(8):509-14.
30. Delalić A, Kapidžić-Duraković S, Tahirović H. Assessment of motor function score according to the GMFM-88 in children with cerebral palsy after postoperative rehabilitation. Acta Medica Academica. 2010 May 10;39(1):21-9.
31. Delalić A, Kapidžić-Duraković S, Tahirović H. Assessment of motor function score according to the GMFM-88 in children with cerebral palsy after postoperative rehabilitation. Acta Medica Academica. 2010 May 10;39(1):21-9.
32. Sawin KJ, Brei TJ, Houtrow AJ. Quality of life: Guidelines for the care of people with spina bifida. Journal of Pediatric Rehabilitation Medicine. 2020 Jan 1;13(4):565-82.
33. Bellin MH, Dicianno BE, Osteen P, Dosa N, Aparicio E, Braun P, Zabel TA. Family satisfaction, pain, and quality-of-life in emerging adults with spina bifida: a longitudinal analysis. American journal of physical medicine & rehabilitation. 2013 Aug 1;92(8):641-55.

34. Lawson N, Papadakis JL, Holmbeck GN. Socioeconomic Status and Parental Perceived Social Support in Relation to Health-Related Quality of Life in Youth with Spina Bifida. The undergraduate research journal of psychology at UCLA. 2018;5:40.