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Quality of Life and Its Associated Factors Among Children with Spina Bifida in Ethiopia: A Cross-Sectional Study to Inform Policy and Practice

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■ BACKGROUND: **Congenital myelomeningocele, or spina bifida (SB), is the predominant congenital anomaly of the central nervous system. Beyond its implications on neonatal mortality, SB impacts the long-term quality of life in affected children. This study sought to investigate the health-related quality of life (HRQoL) among children with SB treated at Ethiopia's leading pediatric neurosurgical facility.**

■ METHODS: **Set at Zewditu Memorial Hospital in Addis Ababa, Ethiopia, this hospital-based cross-sectional study spanned from June 30 to September 30, 2022. It incorporated 232 children, using data gathered through interviewer-led questionnaires. The HRQoL was measured using the PedsQL 4.0, a 23-item generic scale.**

■ RESULTS: **The study's participants had a median age of 5 years (interquartile range = 3 to 6 years). The aggregate mean scores on the PedsQL 4.0 tallied at 68.59 ± 18.01. The lowest scores emerged from queries on school participation, whereas physical and emotional functioning registered the highest scores. Through multiple regression analyses, variables such as family income, monthly household income, number of children, and the presence of a neurogenic bladder showed strong association with HRQoL.**

■ CONCLUSIONS: **This study fills a gap in the literature providing information on the HRQoL and its associated factors for children with SB in low-resourced settings. We champion the proactive integration of quality-of-life metrics into neurosurgical care policy and practice. Given the enduring consequences of SB, interventions honing the HRQoL can steer children toward realizing their intrinsic and enhance societal participation and contribution.**

INTRODUCTION

Spina bifida (SB), also known as meningomyelocele, remains the foremost congenital anomaly of the central nervous system.[1] It belongs to the diverse group of illnesses termed neural tube defects (NTDs). Globally, the suspected prevalence is 18.6 per 10,000 births, acknowledging that 50% of these pregnancies culminate in elective terminations or stillbirths.[2] Furthermore, large geographical disparities are evident.[3] For instance, Africa reports a pooled prevalence of 13 cases per 10,000 births,[4] although Eastern Africa's subregional prevalence reaches 33.3 cases per 10,000 births,[5] 5 times higher than that observed in Western countries. Notably, data from Ethiopia are reported to be higher than the regional average, recording 63.3 cases of NTD per 10,000 births and 41.09 cases of SB per 10,000.[6] Ultrasound-derived prevalence escalates this to 166 per 10,000 pregnancies. Significant regional variations within Ethiopia have been recorded, with Tigray in Northern Ethiopia exhibiting a peak of 64 NTD cases per 10,000 births.[7,8]

Key words
- Adolescents
- Children
- Congenital myelomeningocele
- Quality of life
- Predictors

Abbreviations and Acronyms
GCS: Generic Core Scale
HRQoL: Health-related quality of life
IQR: Interquartile range
NTDs: Neural tube defects
PedsQL: Pediatrics Quality of Life Inventory
SB: Spina bifida
ZMH: Zewditu Memorial Hospital

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Despite the paucity of precise prevalence data, primarily due to over-reliance on hospital-based cross-sectional analyses, and lack of vital registration systems many countries, fueled by folic acid food fortification and prenatal interventions, have seen a significant reduction in prevalence.[9] Concentrated efforts are underway, both nationally and internationally, to counter NTDs through folic acid supplementation before and during pregnancy and exploring robust food fortification approaches.[10,11] NTDs raise neonatal mortality by an average of 10%, further surging to 28% in low- and middle-income countries. Mortality due to NTDs among children under five years was estimated at (0.8 in sub-Saharan Africa and 0.8 in Asia).[12]

While the majority of NTDs are incompatible with life, children with SB, provided they receive timely and comprehensive care, can aspire toward education, employment, and fulfilling lives. Globally, there has been an encouraging progress in delivering neurosurgical, rehabilitative, and psychological care.[13] However, NTD survivors experience considerable physical,[14] economic,[15] and psychosocial[16-18] implications. Meningomyelocele poses significant healthcare challenges, especially for resource-constrained countries where prevention and care strategies are limited. In addition to neonatal survival, the disease markedly diminishes long-term quality of life. Health-related quality of life (HRQoL) encapsulates multifaceted dimensions concerning overall well-being. As survival metrics for SB-afflicted children advance, the consensus gravitates toward assessing the HRQoL as a key outcome measure, which is imperative for decision-making about the management of patients. However, Ethiopia, and a majority of African countries, portray a discernible neglect toward HRQoL for children with SB. Existing research, the majority of which originates from high-income countries, has demonstrated the substantial impact of SB on children's HRQoL,[19,20] with outcomes different geographically based on the employed HRQoL instrument. Several factors, including age, gender, socioeconomic status, family condition, and comorbidities like hydrocephalus, have been linked with HRQoL in children with SB.[20,21] Associations with the level of lesion, incontinence, and ambulatory capacity yield mixed findings.[22,23]

This study was designed to investigate the HRQoL of children with SB and discern factors influencing HRQoL at Ethiopia's largest pediatric neurosurgical hospital, employing the validated age-specific Pediatrics Quality of Life Inventory (PEDSQL) instrument. This research presents the first study to assess the HRQoL in children with SB in Ethiopia. In addition to informing policymakers involved in designing comprehensive care packages and prevention strategies for children with SB, this research, in light of the lack of data correlating symptoms, socioeconomic factors, and HRQoL, intends to highlight modifiable factors that can significantly refine the management of care needs for children with SB.

METHODS

Study Design and Setting

This is a hospital-based cross-sectional study conducted at Zewditu Memorial Hospital (ZMH) in Addis Ababa, Ethiopia, from June 30, 2022, to September 30, 2022. The hospital is one of the only 5 public facilities providing pediatric neurosurgery for children with SB and has the largest patient population in the country. General neurosurgeons launched SB-related services in 2010. Currently, most surgeries are performed in neonates. In addition, ZMH offers follow-up clinic services on Tuesdays and Thursdays every week. Currently, there are 500 patients on follow-up at the clinic. An average of 70 patients attends the clinic every week. We adhered to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) recommendations to prepare this article. The completed checklist is included in the **Supplementary Table 1**.

Patient Enrollment and Data Collection

During the study period, primary caregivers accompanying children over the age of 2 years for routine appointments were approached. Children who have known comorbid medical illness in addition of SB were excluded. Upon obtaining their consent, 4 trained health professionals (2 nurses and 2 general practitioners) administered an electronic Amharic version of the questionnaire, adapted from the PedsQL instrument. Informed consent was obtained from all participating caregivers. The study encompassed a cohort of 232 children (sample size was obtained using a single population proportion formula). Data spanning sociodemographic characteristics, health-related attributes, psychosocial condition of both participants and caregivers and HRQoL were collected.

Measure

The study uses a validated Amharic version of the PedsQL 4.0 Generic Core Scale (GCS) to capture HRQoL.[24] This instrument, with its established reliability and validity, is pertinent for assessing HRQoL in children with both acute and chronic health conditions. The PedsQL 4.0 scale comprises an 8-item physical dimension and a 15-item psychosocial dimension. For parent proxy reports, a 5-point Likert scale was employed (0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem). The questionnaire was sourced from eprovide.mapi-trust.org, with the permissions secured for translation (special terms No. 34085 dated 6 April 2022).

The Amharic version of the PedsQL 4.0 scale was verified to be both reliable and valid for assessing HRQoL among children and adolescents (α child self-report: 0.96; parent proxy report: 0.95). Items were reverse-scored and linearly transformed to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), where higher scores suggest enhanced HRQoL. To compensate for any missing data, scale scores were derived from the total of answered items divided by their count. In instances where more than 50% of the items on the scale are missing, the scale score was not computed.

Statistical Analysis

Data were analyzed using the STATA, version 26. A descriptive analysis was performed to profile the study cohort. Continuous variables were expressed as either median and interquartile range (IQR) or mean and standard deviation. The outcome variables were expressed in terms of mean and standard deviation.

Bivariate analyses, using the relevant test statistic, were performed to determine associations, with the total HRQoL score serving as the dependent variable. We probed the following independent variables for potential associations with total HRQoL: age, sex, caretaker's marital status, educational status of both

parents, family income, presence of hydrocephalus, presence of neurogenic bladder, and child count within the family. The choice of variables was guided by a review of the literature. Only those independent variables that reached a $P < 0.05$ in the univariate analyses were incorporated into the multivariate linear regression model. A P value threshold of 0.05 was taken as the threshold for statistical significance.

Ethical Approval

This study received approval from Institutional Research Review Boards of Gamby Medical College, Addis Ababa Public Health Research and Emergency Management Directorate, and ZMH Hospital. All participants were enrolled in the study after informed consent was obtained. Patients' information was deidentified and stored anonymously.

RESULTS

Study Characteristics

A total of 250 participants were approached for inclusion in the study, and 232 (92.8%) consented to participate. Reasons for exclusion encompassed ten patients attending follow-up visits without a primary caregiver to provide consent and 8 patients refused to participate. Males constituted a slight majority of the sample (n = 123, 53%). The median age of these children and adolescents was five years (IQR = 3–6); a significant proportion (n = 120, 52.72%) were not enrolled in school. Most of the participants (n = 214, 92.2%) resided with both parents (mother and father). The median monthly income of the primary caregivers was 10,000 birr (IQR = 20,000–5000). Moreover, 42 (18.1%) mothers and 15 (6.5%) fathers had no formal education. The majority of children's parents of 211(90.9%) were either married or cohabiting lived together. All single-parent households were headed by mothers. Of the study participants, 108 (46.6%) presented with hydrocephalus, and 91 (39.2%) children manifested a neurogenic bladder concurrent with SB. Furthermore, the majority (n = 199, 85.8%) had attended health education sessions offered during their follow-up visits. See **Table 1** for additional information on participant characteristics.

Pediatric HRQoL of Study Participants

On the PedsQL 4.0 GCS, the total mean score for children and adolescents, based on parent proxy reports, was 68.81 ± 18.01. When stratified by gender, males registered a mean score of 68.1, whereas females registered a mean HRQoL of 69.15. Children aged between 3 and 6 years recorded the lowest mean HRQoL at 63.41, in contrast to those aged over 9 years who marked the highest at 79.15. Lowest scores were obtained in questions referring to school participation, while the highest were in physical and emotional functioning. See **Table 2** for details.

Factors Associated with HRQoL of Children with SB

Factors such as age, sex, family structure, maternal and paternal education levels, family's monthly income, caregivers marital status, and the presence of neurogenic bladder and hydrocephalus were evaluated for potential associations with the child's quality of life using a multivariable linear regression model as delineated by the HRQoL. Normality, linearity, and homoscedasticity of the

Table 1. Sociodemographic and Clinical Characteristics of the Study Participants

Characteristics	N (%)
Sex	
Male	123 (53.02%)
Female	109 (46.98%)
Age category	
0–3 years	18 (7.76%)
3–6 years	127 (54.74%)
6–9 years	64 (27.59%)
9–11 years	23 (9.91%)
Educational status of the child	
Not in school	120 (51.72%)
Kindergarten	57 (24.57%)
Primary school	55 (23.71%)
Family setting: child lives with	
Lives with both parents	214 (92.24%)
Lives with mother	17 (7.33%)
Lives with another caregiver	1 (0.43%)
Maternal educational status	
No formal education	42 (18.1%)
Read and write	19 (8.2%)
Primary education (grades 1–8)	64 (27.6%)
Secondary education[9-12]	45 (19.4%)
College/University	62 (26.7%)
Paternal educational status	
No formal education	15 (6.5%)
Read and write	14 (6.0%)
Primary education[1-8]	63 (27.2%)
Secondary education[9-12]	53 (22.8%)
College/university	85 (36.6%)
Maternal occupation	
Housewife	143 (61.6%)
Daily laborer	1 (0.4%)
Private employee	35 (15.1%)
Civil servant	53 (22.8%)
Paternal occupation	
Daily laborer	58 (25%)
Private employee	79 (34.1%)
Government employee	91 (39.2%)
Other (private/self-organization)	2 (0.9%)
Monthly income in Ethiopian birr	

Continues

Table 1. Continued

Characteristics	N (%)
Low income (<5000)	59 (25.4%)
Middle income (5000–15000)	103 (44.3%)
High income (>15,000)	70 (30.2%)
Primary care givers marital status	
Married and in union	211 (90.9%)
Divorced	19 (8.19%)
Widowed	1 (0.43%)
Separated	1 (0.43%)
Family size	
1–3 children	216 (93.1%)
>3 children	16 (6.9%)
Presence of hydrocephalus	108 (46.6%)
Presence of neurogenic bladder	91 (39.2%)
Attending health education during follow-up	
Yes	199 (85.8%)
No	33 (14.2%)
Hospitalization in the last year	
Yes	5 (2.2%)
No	227 (97.8%)

model were checked to verify the assumptions of linear regression using standard diagnostic tests. In the multiple regression model, monthly income, number of children in the family, and the presence of neurogenic bladder showed strong evidence of association with HRQoL($P < 0.05$) (see **Table 3** below). The model explains approximately a quarter of the variability of total HRQoL scores of children and adolescents ($R2 = 0.216$).

DISCUSSION

In our study, we established that the mean HRQoL for pediatric patients undergoing follow-up at ZMH stands at 68.59, measured using the PedsQL 4.0 GCS on a 0–100 scale. Crucially, we

Table 2. Pediatrics Quality of Life Inventory (PedsQL) Generic Core Scale 4.0 of Children and Adolescents with Spina Bifida

Domain	M	(95% CI)
Physical functioning	61.84	(60.42, 69.26)
School functioning	44.22	(38.95, 49.49)
Emotional functioning	83.33	(81.02, 85.64)
Social functioning	85.42	(83.00–87.83)
Aggregate QoL	68.81	(66.16, 71.46)

CI, confidence interval; QoL, quality of life.

Table 3. Multiple Regression Analysis of Factors Predicting Health-Related Quality of Life in Children and Adolescents with Spina Bifida

	Multivariate Regression Model	
Variable	Unstandardized Coefficient (95% CI)	*P* Value
Single-Parental Family	−8.59 (−14.43, −2.73)	0.004
Family monthly income		
Low (ref)		
Medium	8.83 (3.99,13.67)	<0.001
High	14.49 (7.89,21.09)	<0.001
>3 children in the family	−2.50 (−4.11,-0.889)	0.003
Neurogenic bladder present	−17.48 (−21.25,-13.7)	<0.001

CI, confidence interval.

discerned that the family structure, specifically the number of parents in a household and the number of children, alongside the monthly household income and the presence of neurogenic bladder, played pivotal roles in influencing HRQoL.

These findings resonate with studies underscoring a diminishing HRQoL among children and adolescents with SB,[20,25-27] including those that employed the PedsQL instrument.[28,29] Among the HRQoL domains, it was evident that children struggled the most in areas of physical and school functioning, while their emotional functioning remained relatively robust.

A salient finding from our investigation was the decreased HRQoL observed among children from single-parent households or those with more than 2 siblings. Such outcomes could be attributable to the increased care demands on single parents[30] or the elevated childcare responsibilities in larger families.[31] A strong correlation between household income and HRQoL emerged, where families with more substantial incomes reported better HRQoL scores. This is consistent with findings from previous work undertaken in high-income countries, where higher socioeconomic status positively influences children and adolescents' HRQoL with SB.[32]

An interesting aspect our study uncovered was the association between the presence of neurogenic bladder and a decrease in HRQoL in children with SB. While this echoes findings from a Ugandan study,[33] findings from other countries including the United States, the United Kingdom, and Canada report contrasting results.[20] Urinary incontinence can significantly hamper children's educational and social activities, with repercussions amplified in low- and middle-income countries due to elevated diaper costs, difficulties to access water, sanitation and hygiene facilities and challenges surrounding intermittent self/parent catheterization.[34]

While our study was the first HRQoL report in Ethiopia for this patient group, and we report on a large sample of patients from one of the 5 hospitals in Ethiopia providing pediatric neurosurgical care hence can be generalizable to several settings in

Ethiopia and countries with comparable health systems in Africa, our study is not without limitations. The absence of a control group, the omission of qualitative assessments, the reliance of questionnaire-based assessments for bladder and bowel, and a paucity of literature from analogous settings present challenges. Furthermore, the exclusive reliance on parent-proxy reports of HRQoL might not wholly capture the children's perceptions.

CONCLUSION

This research fills a critical gap in understanding the HRQoL and its associated factors for children with SB in resource-limited contexts. We underscore that family dynamics, household income, and specific health conditions markedly impact HRQoL. Such findings stress the imperative of routinely incorporating HRQoL evaluations into clinical practice, spotlighting areas demanding attention. We argue that HRQoL assessments should guide neurosurgical care policy and practice. Given the lifelong ramifications of SB, interventions optimizing HRQoL can profoundly aid children in realizing their innate potential, thereby boosting their societal contributions. Health educational interventions should be targeted at parents and caregivers to enhance the care provided to these children. While commendable efforts are being made in Ethiopia, such as food fortification with folate to curtail NTD prevalence, there is a pressing need to bolster care for children with SB.

CRediT AUTHORSHIP CONTRIBUTION STATEMENT

Surafeal Tafesse: Writing — review & editing, Conceptualization. **Rocco Friebel:** Writing — original draft, Supervision. **Yonas Mebratu Gebrecherkos:** Writing — review & editing, Formal analysis, Data curation. **Tesfamariam Aklilu Betemariam:** Writing — review & editing, Formal analysis, Data curation. **Tsegzeab Leake:** Writing — review & editing, Writing — original draft. **Meskerem Aleka Kebede:** Writing — review & editing, Supervision, Conceptualization.

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SUPPLEMENTARY DATA

Supplementary Table 1. Bivariate Analysis Output

Variable	Bivariate Analysis: Unstandardized Coefficient (95% CI)	Bivariate Analysis: *P* Value
Age (years)	**2.11 (1.08, 3.15)**	**<0.001**
Female sex	1.05 (-3.6, 5.73)	0.65
Single-parental family	**-18.13 (-26.54, 9.73)**	**<0.001**
Mother's educational status		
No formal education (ref)		
Write & read	9.13 (-0.24, 18.50)	0.056
Primary education	-3.04 (-9.78, 3.68)	0.374
Secondary education	**10.66 (3.38, 17.93)**	**0.004**
College	**8.74 (1.97, 15.52)**	**0.012**
Father's educational status		
No formal education (ref)		
Write & read	-6.92 (-19.33, 5.49)	0.273
Primary education	-3.49 (-12.89, 5.91)	0.465
Secondary education	4.07 (-5.51, 13.66)	0.403
College	7.37 (-1.76, 16.51)	0.113
Marital status		
Divorced (ref)		
Married	8.57 (-3.58, 20.72)	0.16
Widowed	-0.37 (-35.41, 34.66)	0.983
Family monthly income		
Low (ref)		
Medium	**9.69 (4.36, 15.01)**	**<0.001**
High	**19.46 (13.69, 25.22)**	**<0.001**
>3 children in the family	**-4.22 (-6.30, -2.13)**	**<0.001**
Hydrocephalus present	**-7.23 (-11.82, -2.65)**	**0.002**
Neurogenic bladder present	-20.05 (-24.06, -16.04)	<0.001

Bold values indicate that those variables are selected for multivariable regression.
CI, confidence interval.