Quality of life of patients under 15 years of age with Myelomeningocele on follow up at Zewditu Memorial and Tikur Anbessa Specialized Hospital Addis Ababa, Ethiopia; A Multicenter Cross-Sectional Study

A research thesis to be submitted to the Department of Pediatrics and Child Health, School of Medicine, College of Health Sciences, Addis Ababa University as partial fulfillment of the requirements for specialty certificate in pediatrics and child health

Investigator:

Kefele Elias, MD

Pediatric and Child Health Resident

Advisor:

Professor Damte Shimelis
Consultant Pediatrician & Pediatric Nephrologist

Professor of Pediatrics and Child Health

February 2025

APPROVAL SHEET

ADDIS ABABA UNIVERSITY, COLLEGE OF HEALTH SCIENCES, SCHOOL OF MEDICINE, DEPARTMENT OF PEDIATRICS AND CHILD HEALTH

I, the under signed Pediatrics and Child health resident, declare that I have submitted my original research thesis on the title Quality of life of patients under 15 years of age with Myelomeningocele on follow up at Zewditu Memorial and Tikur Anbessa Specialized Hospital Addis Ababa, Ethiopia; in partial fulfillment of the specialty program.

Submitted by:

Name of resident **Signature** **Date**

Dr. Kefele Elias

This A research thesis work has been submitted with my approval as an advisor.

Approved by:

Primary Advisor **Signature** **Date**

Professor Damte Shimelis

February 2025

Table of contents

February 2025

List of Tables

List of Figures

Acronyms

- MD – Medical doctor
- HRQOL – Health related quality of life
- QOL – Quality of life
- TASH – Tikur Anbessa Specialized Hospital
- SPSS - Statistical Package for Social Sciences
- PI - Principal investigator
- MMC-Myelomeningocele
- SB -Spina bifida
- ZMH-Zewditu memorial Hospital
- GCS: Generic Core Scale
- PedsQL: Pediatrics Quality of Life Inventory
- NTDs: Neural tube defects
- IQR: Interquartile range

Acknowledgment

I would like to express my deepest gratitude to Addis Ababa University College of Health Sciences, Department of Pediatrics and Child Health for allocating the budget and giving me the chance to do this research. I would also like to express my gratitude to Zewditu memorial hospital administration and neurosurgery unit for their cooperation and creation of conducive environment for the research. I would like to express my respect to my advisor Professor Damte Shimelis for his invaluable comments and Guidance throughout the development of this research Thesis and for his interest and readiness to help me until the end of the study.

February 2025

Abstract **Background –** Africa was shown to have a high pooled birth prevalence of neural tube defects. Despite the use of preventative measures, the prevalence of neural tube defects in Ethiopia is seven times higher than in other Western nations. Despite the heavy burden, there have been relatively few studies on the quality of life of children with myelomeningocele, particularly at the multidisciplinary level. The long-term quality of life is impacted by MMC.

Objective: The objective of this study was to assess quality of patients under 15 years of age with Myelomeningocele On follow-up at Zewditu Memorial and Tikur Anbessa Specialized Hospitals.

Methods: The study was a multicenter cross-sectional study that was carried out at the neurosurgery clinics of Zewditu Memorial and Tikur Anbessa Specialized Hospital between September 2024 and February 2025. Data was gathered from patients who met the requirements using a simple random sampling method and questionnaires that the parents completed with the researcher's help. Version 25 of the Statistical Package for Social Sciences (SPSS) was used to enter the data for any ensuing descriptive and analytical statistics. In terms of statistics, a p-value of less than 0.05 was considered to indicate a significant association
.

Result: A total of 215 study participants participated during the study period, yielding a 95.9% response rate. 54 percent of the children were female, and the majorities (89.8%) were between the ages of 0 and 7. The study's overall QoL result was 45.1±20.24. Comparing school functioning (33.43±18.56) and emotional functioning (36.5±16.85) to other general scoring measures, the QoL values were lower. With a mean score of 56.6±30.71, physical functioning was the highest, followed by social functioning (38.17±23.78). Our research reveals a strong relationship between household income and HRQoL, with higher-income households reporting higher HRQoL ratings. When compared to patients with concomitant conditions, MMc patients without comorbidity have a higher overall quality of life.

Conclusion In conclusion, the results of this study demonstrated that, in comparison to several studies conducted in other nations, children with MMC at Zewditu and Black Lion Hospital Neurosurgery unit had usually low quality of life assessment scores. Additionally, when compared to other generic scoring scales, the QoL ratings were higher for physical functioning and lower for school functioning.

1. Introduction

1.1 Background

A group of congenital conditions known as spinal bifida (SB) are brought on by the developing neural tube's incomplete closure. The most common type of SB lesion, known as myelomeningocele (MMC), is characterized by the spinal cord protruding beyond the canal. MMC is linked to more serious neurologic effects than the closed variety (non-myelomeningocele). A wide range of clinical symptoms, such as lower extremity weakness, diminished feeling, bowel and bladder dysfunction, abnormalities of the bones and joints, and sexual dysfunction, can result from any type of SB.

About 40 out of every 100,000 live babies worldwide are affected with SB each year. Early on, the main focus of SB care was on medical and surgical measures to lower morbidity and increase life expectancy. The life expectancy of these patients has significantly increased over the past few decades, rising from roughly 15 years in 1956 to nearly as high as that of the general population today due to swift and ongoing advancements in surgical and medical therapy. According to conservative estimates, there are currently at least 166,000 people in the US who have SB, with adults making up the majority. Since more patients are living to adulthood, it's critical to broaden the scope of academic research to take long-term quality of life (QOL) factors into account. Although there has been some attempt to look into QOL outcomes, there isn't much study looking at long-term patient outcomes or possible ways to raise QOL. The few studies that are currently available concentrate more on function than on SB patients' perceptions and experiences. It will be crucial to move away from short-term, immediate surgical success and toward long-term QOL measurements. It has been demonstrated that accurate measurement and application of these indicators enhance patient happiness, results, and clinical decision-making. Furthermore, urologists should pay special attention to quality of life (QOL) because many of the symptoms they treat are chronic and might affect a patient's psychosocial state (e.g., bladder, self-esteem, and sexuality). As a result, numerous experts in the field have advocated using QOL metrics to enhance patient care customization and individualization (1).

Africa was shown to have a high pooled birth prevalence of neural tube defects. Algeria and Tunisia were found to have the highest and lowest rates, respectively (2).

The most prevalent anatomical type of spinal bifida in South Africa is myelomeningocele, which accounts for about 85% of lesions. Depending on the region under consideration, there are also differences in the gender distribution of people born with myelomeningocele. Genetic and dietary risk factors are the most well-established groups of risk variables for myelomeningocele development. Prenatal neural tube defect diagnosis is now possible thanks to modern prenatal screenings using alpha-fetoprotein and ultrasound. The clinical type and degree of spina bifida determine its clinical manifestation.A midline anomaly in the lumbosacral area is frequently the presentation of myelomeningocele. Additional abnormalities are linked to myelomeningoceles. Although about 10% of newborns are born with clinically noticeable hydrocephalus, this incidence

rises dramatically in the first week of life, with up to 85% of cases exhibiting hydrocephalus. Additionally, the Arnold Chiari 2 malformation is present in nearly all myelomeningocele patients. Although myelomeningoceles are often surgically closed within the first 48 hours of life, the development of a generally safe fetal surgical closure technique has shown significant benefits. (3,4)

The age of the kids and their emotional functioning were shown to be strongly and significantly correlated negatively. Age-related declines in functioning in this region were 1.5 points on average each year of age. The physical, social, and academic functioning of children without hydrocephalus was considerably better than that of children with this condition ($p < 0.05$). The children's physical functioning was negatively impacted by foot abnormalities in a substantial way ($p = 0.033$). In all of the domains examined, being in a single-parent household had no statistically significant effect on functioning ($p > 0.05$). Conclusion: Planning measures to reduce the negative effects of the illness may be made easier with an understanding of the quality of life (QoL) of children with MMC and the identification of its factors (5).

From June 30 to September 30, 2022, a hospital-based cross-sectional study on Quality of Life and Its Associated Factors Among Children with Spina Bifida was conducted at Zewditu Memorial Hospital in Addis Ababa, Ethiopia. It used information obtained from interviewer-led questionnaires and included 232 youngsters. The 23-item generic PedsQL 4.0 was used to measure HRQoL. On the PedsQL 4.0, the total mean scores came to 68.59+/- 18.01. School involvement questions yielded the lowest scores, while questions about physical and emotional functioning yielded the greatest ratings. Multiple regression analyses revealed a substantial correlation between HRQoL and covariates such family income, monthly household income, number of children, and the presence of a neurogenic bladder (6).

1.2 Statement of the problem

Much is unknown regarding the quality of life of myelomeningocele patients, despite the fact that the disease is very common in Africa, particularly Ethiopia, where there are numerous cases in comparison to Western nations. From June 30 to September 30, 2022, Zewditu Memorial Hospital in Addis Ababa conducted a cross-sectional study on Quality of Life and Its Associated Factors among Children with Spina Bifida in Ethiopia. The study's total mean scores on the PedsQL 4.0 came to 68.59 +/- 18.01. School involvement questions yielded the lowest scores, while questions about physical and emotional functioning yielded the greatest ratings. Multiple regression analyses revealed a substantial correlation between HRQoL and covariates such family income, monthly household income, number of children, and the presence of a neurogenic bladder.

1.3 Significance of the study

To the best of the author's knowledge, there is a lack of representative empirical data regarding the quality of life of patients with MMC, particularly in the pediatric department, at the national level. Establishing resource allocation priorities for management and follow-up requires information, which is extremely important. The quality of life of individuals with MMC is currently poorly understood. According to the parents or patients in our setup, this study will provide us with information regarding the quality of life of patients with MMC. Additionally, it will serve as a basis for future prospective research on the quality of life of patients with MMC and guide organizational and system-level policies and practices that endeavor to enhance the quality of life for those with MMC and develop various approaches for a more equitable distribution of services for those impacted. Healthcare practitioners will be better equipped to meet the requirements of the population if they have a thorough understanding of the quality of life (QoL) of children and adolescents with MMC and how it relates to associative factors that either improve or worsen children's QoL.The study helps to Reproduce (strength the findings of previous study at Zewditu Memorial Hospital or may come with different results. This study also helps to see health related quality of life of patients from pediatrics point of view since MMC Management and follow up need multidisplannary team involvement.

2. Literature Review

Standardized HRQOL measures were completed by 50 patients with MMC aged 8–16 (28 females and 22 males) from three German pediatric clinics, along with their mothers. Nine patients had thoracic lesions, twenty-five had sacral lesions, and eleven had lumbosacral lesions. Seven patients used a wheelchair, seventeen were able to walk in their homes, and twenty-one were community walkers. Eight patients had a shunt, six had hydrocephalus, and ten had a tethered cord, indicating that two-thirds had health issues relating to the central nervous system that were causing them to struggle now.When compared to norm data, patients in the study group reported lower overall HRQOL, particularly in the areas of peer relationships, emotional well-being, and self-esteem. In the area of peer relationships, adolescents reported lower HRQOL. Our findings highlight the significance of peer relationships in young patients with MMC and support research that challenges a linear inverse relationship between disease severity and HRQOL. (7)

Parents of children with myelomeningocele receiving specialized care through the Association of Patients with Myelomeningocele in Poland participated in a descriptive, correlational, cross-sectional study conducted in the first quarter of 2019. 52 children between the ages of 2 and 18 had parent proxy-report data included in the sample. MMC was found in the lumbar-sacral region in 62% of children, the thoracolumbar region in 33%, and the lumbosacral region in 5% of children. 23% of patients had Arnold-Chiari syndrome, while 43% of patients had hydrocephalus. According to the psychological questionnaire, 31% of the children had below-average intellectual development, 7% had mild intellectual disability, 6% had moderate intellectual disability, and 5% had severe intellectual disability.

42.3% of the patients experienced pain, and over half of them required a wheelchair. Being in a single-parent household did not significantly affect functioning in any of the examined domains, including EF ($p > 0.05$). Children whose parents were employed had a significantly lower mean number of hospitalizations than children whose parents were not employed ($p = 0.044$). Compared to fathers, mothers were more likely to quit their jobs (28 vs. 4, $p = 0.003$). 56.4 (SD ± 14.7) was the overall PedsQL Generic Core score. Emotional, social, and school/preschool/nursery functioning were all substantially higher than physical functioning.

The lowest rating was given to physical functioning, which includes self-care, mobility and activity (walking, running, playing sports, or exercising), and symptoms including pain and exhaustion (total score: 41.8, SD = 20.1). Emotional functioning (total score: 63.9, SD = 14.5), which includes emotions like fear, sadness, or anger as well as difficulty sleeping, was the most highly scored component. The age of the kids and their emotional functioning were found to be strongly and statistically significantly correlated negatively. Age-related declines in functioning in this region were 1.5 points on average each year of age. The children's physical functioning was considerably ($p = 0.040$) impacted by the presence of a neurogenic bowel. (7)

At a mean follow-up of six years, children with myelomeningocele (MMC) who arrive with leaky MMC, hydrocephalus, Chiari malformation, or lower limb paralysis at birth had a considerably worse quality of life. (8).

Between the ages of 5 and 30, the annual mortality rate for patients with spina bifida is approximately 1%. Morbidity and mortality increase with the size of the lesion. The effects of neural tube abnormalities have a significant negative influence on survivors' quality of life. This group is prone to psychosocial problems such as elevated rates of anxiety, depression, and risk-taking behaviors. Employment, romantic connections, and financial independence are the areas most likely to be impacted, according to studies (9).

Bladder catheterization is the primary challenge in the care of children with meningomyelocele. As a result, the families of these kids also have to deal with stigmas and biases around motor impairments as well as fecal and urine incontinence. Both impede social interactions. According to a study examining family caregivers' attitudes toward providing daily care for children with MMC (such as catheterization), doctors should be involved, and a psychologist may even be required to collaborate with the interdisciplinary team so that these professionals can handle emotional challenges with all parties involved in this exhausting process. (10)
A study on the medical, functional, and social factors influencing health-related quality of life in people with myelomeningocele was conducted in Boston, USA. The study included a prospective enrollment of 18 female and 16 male patients with myelomeningocele (mean age 13 years, SD 6 years; range 4 to 27 years). Compared to children with hydrocephalus alone, children with myelomeningocele with and without hydrocephalus scored poorer on quality of life measures for mobility, continence, and self-care. Children with hydrocephalus performed worse on tests of communication, eyesight, concerns, and school activities. (11)

The Impact of Operation Duration on the Prognosis of Infants with Meningomyelocele Journal of the Korean Neurosurgical Society A retrospective analysis was conducted on the medical records of thirty newborns who had meningomyelocele. Patients were split into two groups according to when they had surgery (group 1, ≤5 days; group 2, >5 days). Comparisons across the groups showed that earlier surgery was linked to considerably shorter hospital stays ($p<0.001$) and antibiotic treatment ($p<0.05$). (12)

Ethiopian Children with Spina Bifida and Their Quality of Life and Related Factors From June 30 to September 30, 2022, this hospital-based cross-sectional study was conducted at Zewditu Memorial Hospital in Addis Ababa, Ethiopia. It used information obtained from interviewer-led questionnaires and included 232 youngsters. The 23-item generic PedsQL 4.0 was used to measure HRQoL. The median age of the study participants was five years, with an interquartile range of three to six years. On the PedsQL 4.0, the total mean scores came to 68.59 +/- 18.01. School involvement questions yielded the lowest scores, while questions about physical and emotional functioning yielded the greatest ratings.Multiple regression analyses revealed a substantial correlation between HRQoL and covariates such family income, monthly household income, number of children, and the presence of a neurogenic bladder. (6)

3. Objectives

3.1. General objectives

To Assess the Quality of life of patients under 15 years of age with Myelomeningocele on follow-up at Zewditu Memorial and Tikur Anbessa Specialized Hospital.

3.2. Specific objectives

To determine the effect of the disease on the social functioning of patients
To analyze the effect of the disease on the school performance of patients
To describe the effect of disease on the emotional functioning of patients
To explain the effect of disease on the physical functioning of patients

4. Materials and methods

4.1 Study setting

Zewditu Memorial and Tikur Anbessa Specialized Hospital in Addis Ababa, Ethiopia, served as the study's sites. The largest tertiary hospital in the nation is Tikur Anbessa Specialized Hospital, which opened its doors in 1974. The largest and oldest teaching hospital in Ethiopia, it is run by Addis Ababa University and serves approximately 350 residents and 300 medical students annually. Approximately 400,000 people are diagnosed and treated annually by TASH. Zewditu Memorial Hospital has the most patients in the nation and is one of just five public hospitals offering pediatric neurosurgery for kids with SB.In 2010, general neurosurgeons began offering services linked to SB. Nowadays, newborns are used for the majority of procedures. Furthermore, ZMH provides four days a week of follow-up clinic services.

4.2 Study Design and Study Period

Using the Pediatric Quality of Life Inventor (PedsQLTM) 4.0 general core scale (parent report form), which is freely available to students, doctors, and clinical practice, this hospital-based cross-sectional study was carried out between September 2024 and February 2025.

4.3 Source Population

All children under 15 years of age with MMC on follow-up at Zewditu Memorial and Tikur Anbessa specialized hospital.

4.4 Study Population

224 children on follow up with MMC at Zewditu memorial and Tikur Anbessa specialized hospital.

4.5 Sample size

The following presumptions will be taken into account when calculating the overall sample size using the single population proportion formula.
5% margin of error with 95% CI
P = 0.34 (33.9/10000)
The sample size was determined using the following formulas: n = Z 2 P (1-P)/d2 n = 345
where n is the smallest possible sample size.
P is the SB prevalence.
d is the margin of error
Z is the 95% confidence level value.
Applying sample size adjustment to a population that is limited:
NZ2P (1-P) d2 (N-1) / Z2 P (1-P), where N (population size) = 500)

n = 204
The sample size with an additional 10% of non-respondents was 224.

4.6 Sampling Method

A simple random sampling technique was applied. All parents or primary caregivers who brought their kids to follow-up appointments during study time frame were invited to participate, as long as they fulfilled the predetermined inclusion requirements. Enrollment persisted until the study's required sample size was reached.

4.7 Inclusion and Exclusion Criteria

Criteria for inclusion

All patients with MMC under 15 years of age on follow-up at Zewditu Memorial and Tikur Anbessa specialized hospital.

Exclusion criteria

Patients or Parents with age > or =15 years

Parents or other major caregivers who refuse to grant their permission

4.8 Data collection and measurement

4.8.1 Pre-test questionnaire

Five children who were attending follow-up appointments at TASH's pediatric neurosurgery section participated in a pilot test to make sure the questionnaire worked as intended. The study's findings did not include these people. The standard questionnaire was improved using the knowledge gathered from the five-child pilot test. In particular, a few questions needed to be modified to better fit our community's social and cultural standards.

4.8.2 Questionnaire

To collect data about the participants' and their children's sociodemographic , health-related and psychosocial state, we used a clear, pre-tested questionnaire. The PedsQL TM 4.0 generic core scales were used to score the questionnaire's QoL. Physical functioning, emotional functioning, social functioning, and school functioning are the four dimensions that make up its twenty-three items. It has five scales, ranging from 0 (never) to 4 (nearly always) and Scores were converted on a scale from 0-100 .Better HRQoL is indicated by a higher score. In order for the parents or caregivers to grasp this grading approach, the data collectors clarified any unclear points and presented it in straightforward language. The local language was used to translate the questionnaire. A particular protocol detailing the data gathering procedure was created in order to guarantee accurate and consistent data collection. Additionally, this approach served as the basis for training data collectors.

.

4.8.3 Data Handling

The investigator in charge has verified the completeness and cleanliness of the data. Backup copies were kept on a different drive, and the hard copies were transformed into soft copies, saved on a hard disk, and prepared for analysis.

4.9. Study Variables

4.9.1 Independent variables

Sociodemographic data: Age, sex, parental marital status, highest educational attainment of the primary caregiver, monthly household income, job status of the primary caregiver, and child's educational status, address.

Other health-related data – Gestational age at birth,associated comorbidities (Hydrocephalus, lower extremity paresis or paralysis), Foot deformity, Time of surgery.

4.9.2 Dependent variables

Patients' quality of life
The patients' social functioning
Patients' academic performance
The patients' emotional functioning
The patients' physical functioning

4.9 Data Quality Assurance

(principal investigator) carried out routine monitoring to guarantee the accuracy and completeness of the data.

4.11 Data Analysis and Interpretation

Following a thorough cleaning and completeness check, the data was entered into SPSS version 25, a statistical software program, for further analysis, including the calculation of means, frequencies, and percentages as needed. For all statistical tests, a p-value of less than 0.05 was considered statistically significant.

5. Ethical Consideration

The Research and Publications Committee of the School of Medicine, College of Health Sciences, Addis Ababa University, Addis Ababa Health Bureau, and Zewditu Memorial Hospital provided ethical clearance for the study. The goal of the study and how the data collected from the respondents would be used were explained to them. Additionally, they were informed of the study, their complete right to remain silent, and their freedom to end the interview at any time. Participants in the study provided written, informed consent. Confidentiality of participants was guaranteed.The same high standard of medical treatment was provided to parents who declined to participate in the trial as to those who did. The participants' identities were kept totally private during the analysis and publication of the study's results.

6. Dissemination of findings

This study's results will be presented both graphically and tabularly. On the day of the research defense, the study's findings will be presented, and both hard and soft copies of the formal report will be delivered to Zewditu Memorial Hospital and Department of Pediatrics and Child Health. Additionally, the results of the research will be published in national or international scientific journals.

7. Operational definitions

Neural tube defects and MMC

There are two types of neural tube defects: an open neural tube defect is one that is either completely covered by a membrane or only partially covered. It makes up almost 80% of all defects of the neural tube. (13) Closed neural tube defect: This condition, which typically arises from a defect in the fat, bone, or membranes surrounding the spinal cord, has no outwardly noticeable abnormality. (13) The most prevalent open neural tube defect is myelomeningocele, also known as meningomyelocele, a debilitating congenital abnormality of the central nervous system. It is characterized by a vertebral abnormality that causes the meninges and spinal cord to herniate because the neural tube fails to close in the lumbosacral area during embryonic development (fourth week post-fertilization).
Beginning at the level of the hindbrain (medulla and pons), the neural tube fusion advances both caudally and rostrally. Around day 26 of pregnancy, meningomyelocele forms as a result of incomplete fusion caudally. (13)

Arnold Chiari 2 malformation

Is a complicated congenital brain abnormality that is almost invariably linked to myelomeningocele. Skull, dural, brain, and spinal cord symptoms of this syndrome include elongation of the pons and fourth ventricle, likely because of a relatively small posterior fossa, and downward displacement of the medulla, fourth ventricle, and cerebellum into the cervical spinal canal (14)

Quality of Life

"People's views of their place in life within the framework of the culture and value systems in which they live to goals, expectations, standards, and concerns" is how the WHO defines quality of life (15).

Health-related quality of life

Health-related QoL measures how much a sickness or medical condition affects a person's everyday physical, emotional, mental, and contextual well-being. Stated differently, it represents the individual's subjective view of health. (15)

Neurogenic bladder

Any mechanical or physiological flaws in the micturition system that cause the urinary sphincter to be unable to react effectively to elevated bladder pressure by raising or lowering its pressure might cause voiding dysfunction. Neurogenic bladder dysfunction can be caused by disorders or damage to the central, peripheral, and autonomic neural systems. (16)

Peds QL^{TM} Generic score scale

The standard generic core QoL scale for assessing the physical and mental well-being of both healthy and sick children is the Pediatric Quality of Life Inventor (PedsQLTM) 4.0. (17)

8. Results

8.1 Socio-demographic Characteristics

There were 215 study participants in all, with a 95.9% response rate, during the study period, which ran from September 1 to February 1, 2025.

The majority of the respondents (78.6%) were mothers, and 70% of them were between the ages of 30 and 50. The Oromo ethnic group made up 32.6% of them, and 45% of them identified as orthodox. In terms of marital status, over 77% of the parents were married, and 30.7% of the mother had finished secondary school. 53% of the participants' households made between $40 and $120 per month, 47% of the mothers were housewives, and 31% of the parents had completed college or higher educational level.

Table 1 -Details of socio-demographic characteristics of parents/caregivers

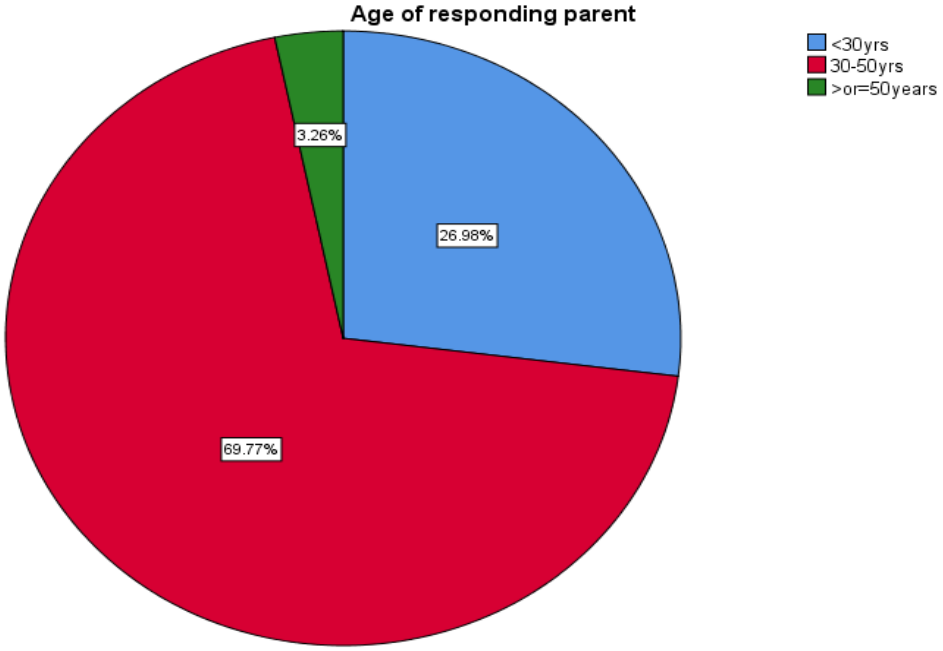

Figure-1 Age of Respondent Parents

Table1. **Sociodemographic characteristics of the study participants**.

Variable	**Frequency**	**Percent**
Age of the respondent in years		
<30	58	27
30-50	150	69.8
≥50	7	3.3
Relation to the patients		
Mother	169	78.6
Father	40	18.6
Caregiver	6	2.8
Ethnicity		
Amhara	63	29.3
Oromo	70	32.6
Tigrai	17	7.9
Other	65	30.2
Religion		
Orthodox	97	45.1
Muslim	79	36.7
Protestant	39	18.1
Marital status		
Married	165	76.7
Divorced	23	10.7
Widowed	2	.9
Single parent	22	10.2
Separated	3	1.4
Maternal Education level		
Illiterate	57	26.5
Completed primary education	66	30.7
completed secondary education	43	20.0
College diploma/degree and above	49	22.8
Paternal educational Status		
Illiterate	29	13.5
Completed primary education	75	34.9
Completed secondary Education	44	20.5
College Diploma/Degree and Above	67	31.2
Maternal occupation		

House Wife	101	47.0
Self-employee	48	22.3
private employee	38	17.7
Government employee	28	13.0
Paternal occupation		
Unemployed	20	11.1
Self-employee	70	38.9
Private employee	47	26.1
Government employee	43	23.9
Family monthly income		
<40$	73	34.0
40-121	114	53.0
>121$	24	11.2

8.2 Children's demographic related characteristics

Majority (89.8%) of children were 0-7 years of age,3.3% age 13-15 and the remaining were in the age range of 8-12 .Regarding sex distribution fifty-four percent(54%) of the children were female.67.4% were diagnosed by imaging and 92.6% of patients had no comorbid disease.

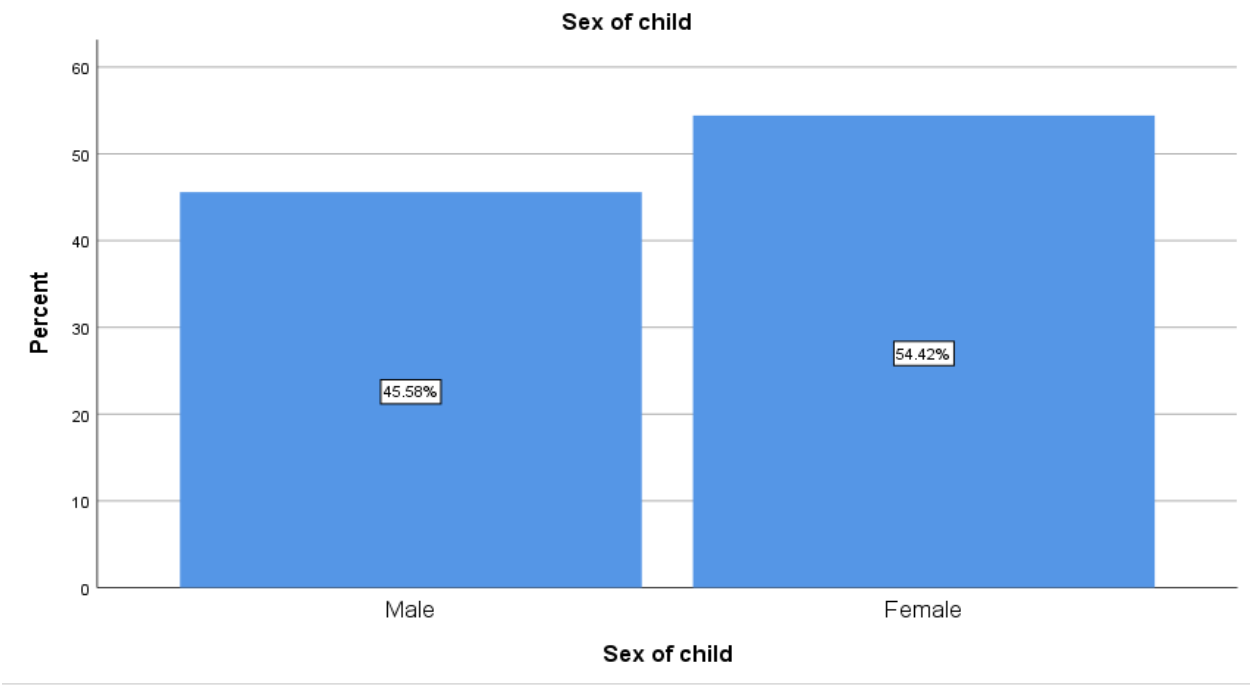

Figure-2 Sex distribution of children's with MMC

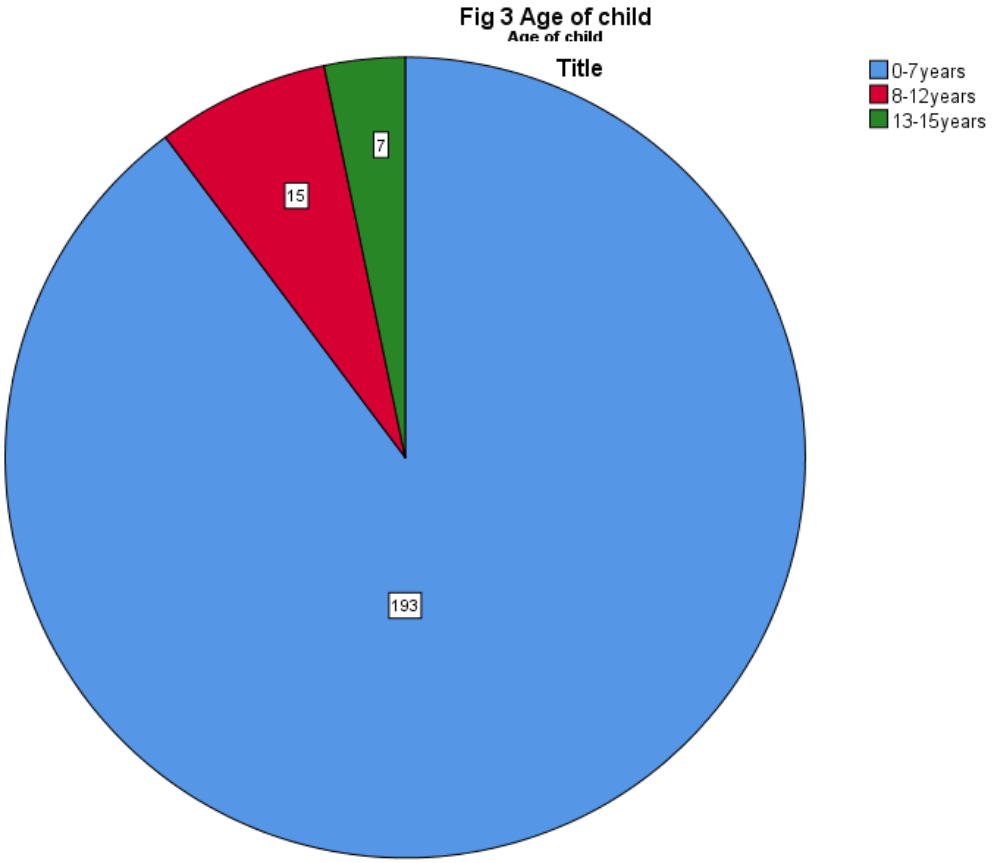

Fig-3 Age of the child

Table2. Children's demographic related characteristics

Variable	Frequency	Percent
Gestational age at birth in weeks		
<37	74	34.4
>=37	141	65.6
Age of the child in years		
0-7	193	89.8
8-12	15	7.0
13-15	7	3.3
Sex of the child		
Male	98	45.6
Female	117	54.4
Mode of diagnosis		

Clinical	70	32.6
Imaging	145	67.4
School grading		
KG	45	75
Elementary	12	20
Secondary	3	5
Comorbidities		
No comorbidity	199	92.6
Clubfoot	4	1.9
Other comorbidity	12	5.6

8.3 Myelomeningocele related characteristics

84.2% of the lesion was in the lumbosacral area, and 86% of the children were diagnosed before 72 hours of age. 39.1% of the children had renal follow-up, and 89% of the children underwent surgery. 73.5% of the children had neurologic bladder, and 55% of the youngsters had hydrocephalus. According to the table below, 74% of the children had urine incontinence and 69% of the children had bowel incontinence.

Table 3.Myelomeningocele related characteristics

Variable	Frequency	Percent
Age at diagnosis		
<72hrs	184	85.6
72hrs-1month	8	3.7
≥1month	23	10.7
Site of lesion		
Above lumbosacral	34	15.8
At lumbosacral	181	84.2
Operated children		
Yes	193	89.8
No	22	10.2
Age during time of operation		
<1weeks	34	15.8
1week-1month	83	38.6
>=1month	98	45.6
Renal clinical follow up		
Yes	84	39.1
No	131	60.9

Presence of hydrocephalus		
Yes	118	54.9
No	97	45.1
Neurogenic bladder		
Yes	158	73.5
No	55	25.6
Attending health education during illness follow up		
Yes	202	94
No	13	6
Bowel incontinence		
Yes	149	69.3
No	66	30.7
Urinary incontinence		
Yes	159	74
No	56	26
Post op CSF leak		
Present	78	36.3
Not present	137	63.7
Lower motor weakness present during time of diagnosis		
Yes	184	85.6
No	31	14.4
Has the childs illness forced the parent to quit their job		
Yes	163	75.8
No	52	24.2
Which parent resigned from their job		
Mother	187	87.0
Father	28	13.0

8.4 Results for generic core scales using PedsQL 4.0

Physical functioning, social functioning, emotional functioning, and school functioning were among the topics included in the PedsQL 4.0 generic core scales questionnaire. With a five-point rating system (ranging from 0 to 4 points depending on how much each statement was agreed with), there were 23 questions in all. After that, the results were converted into full scores of up to 100 points in each category; 100 points indicated an excellent quality of life with no issues, while 0 points indicated a quality of life with almost continual issues.

The average scores from the questions that were answered made up the total scores for each functional area. Unresolved queries were left out. Scores were not computed if more than half of the questions were left unanswered. The average scores for the four functional areas made up the total QoL scores. Comparing school functioning (33.43±18.56) and emotional functioning

(36.5±16.85) to other general scoring measures, the QoL values were lower. With a mean score of 56.6±30.71, physical functioning was the highest, followed by social functioning (38.17±23.78). The study's overall QoL result was a mean of 45.1. The score ranged from 0 to 80.1, with the interquartile range being 61.7 to 26.5 and the 50th percentile being 50.

Table 4.The mean and median of the subgroup QOL

Types of QOL measurement	Mean ±SD	Median	minimum	Maximum
Physical functioning	56.6±30.71	67.86	0	100
Emotional functioning	36.5±16.85	35	0	95
Social functioning	38.17±23.78	40	0	95
School functioning	33.43±18.56	35	5	85
Total/overall	45.1±20.24	50	0	80.9

8.5 The specific types of quality-of-life measurement among the study participants

Regarding Physical functioning, twenty-nine percent of the children were always having problem in walking more than one block and 21.9% of the children were never experiencing problem in running. Fifty-one percent of the children(51%) were having almost always problem in participating in sports and exercise. Forty-three percent(43%) of the children had sometimes experience low energy level and 32.6% were never feeling afraid or scared.About 2.3 percent of respondents were having worrying about what will happen to him/her.

Table5. The specific types of quality-of-life measurement among the study participants

Variable	Never	Almost never	sometimes	Often	Almost always
Physical functioning					
Walking more than one block	67(31.2%)	21(9.8%)	38(17.7%)	27(12.6%)	62(28.8%)
Running	47(21.9%)	31(14.4%)	14(6.5%)	33(15.3%)	90(41.9%)
Participating in sports & exercise	30(14%)	37(17.2%)	18(8.4%)	20(9.3%)	110(51.2%)
Lifting something heavy	24(11.2%)	39(18.1%)	20(9.3%)	17(7.9%)	115(53.5%)
Taking bath or shower by him self	22(10.2%)	32(14.9%)	29(13.9%)	15(7%)	117(54.4%)
Having hurts or aches	34(15.8%)	38(17.7%)	108(50.2%)	17(7.9%)	18(8.4%)
Low energy level	48(22.3%)	49(22.8%)	93(43.3%)	12(5.6%)	13(6%)
Emotional functioning					
Feeling afraid or scared	70(32.6%)	65(30.2%)	69(32.1%)	6(2.8%)	3(1.4%)
Feeling sad or blue	18(8.4%)	40(18.6%)	107(49.8%)	36(16.7%)	12(5.6%)
Feeling angry	39(18.1%)	86(40%)	57(26.5%)	17(7.9%)	14(6.5%)
Trouble with sleeping	32(14.9%)	49(22.8%)	106(49.3%)	25(11.6%)	1(0.5%)
Worrying about what will happen to him/her	56(26%)	82(38.1%)	47(21.9%)	23(10.7%)	5(2.3%)
Social functioning					
Getting along with other children	68(31.6%)	58(27%)	65(30.2%)	17(7.9%)	5(2.3%)
Other children are unwilling to be his or her friends.	53(24.7%)	52(24.2)	60(27.9%)	39(18.1)	11(5.1%)
Getting teased by other children	45(20.9%)	74(34.4%)	66(30.7%)	23(10.7%)	7(3.3%)
Not able to do things that other children his/her age can do	43(20%)	48(22.3%)	70(32.6%)	36(16.7%)	18(8.4%)
Keeping up with other kids when they're playing	39(18.1%)	50(23.3%)	74(34.4%)	39(18.1%)	13(6.1%)
School functioning					
Paying attention in class	27(46.6%)	15(25.9%)	9(15.5%)	3(5.2%)	4(6.9%)
Forgetting things	23(45.1%)	13(25.5%)	11(21.6%)	4(7.8%)	
Keeping up with school work	3(5.9%)	14(27.5%)	20(39.2%)	11(21.6%)	3(5.9%)
Missing school because not feeling well		10(19.6%)	31(60.8%)	5(9.8%)	5(9.8%)
Missing school to go to hospital		10(19.6%)	31(60.8%)	5(9.8%)	5(9.6%)

8.6 Ordinal Multivariate logistic regression of association between QOL and independent variable among children having Myelomeningocele

Our research reveals a significant correlation between household income and HRQoL, with higher-income households reporting higher HRQoL ratings.Regarding Occupation self-employed and private employed mothers and fathers have poor overall quality of life than Government employed parents.MMc Patients with No comorbidity has good overall quality of life compared with those

with comorbid illness.Analysis of our result shows presence of lower motor weakness is associated with poor overall quality of life.

Table-6 Multiple regression Analysis of independent factors affecting Quality of Life

Variable	**AOD(95%CI)***	**P-Value**
Married	-47.97(-95.26,-.70)	0.04
Fathers who completed primary education	50.24(6.60,93.88)	0.024
Self Employed Mothers	-55.19(-98.71,-11.66)	0.013
Private employed mothers	-62.15(-111.3.-11.01)	0.013
Self-employed Fathers	-36.61(-67.95,-5.27)	0.022
Private employed Fathers	-38.90(-70.81,-6.99)	0.017
Parents with income greater than or equal to 121$	42.09(5.44,78.74)	0.024
No comorbidity	43.31(1.09,85.52)	0.044
MMC operated b/n 1week and 1month	-18.51(-34.83,-2.18)	0.026
Presence of CSF leak	36.85(6.21,63.49)	0.017
Presence of lower motor weakness	-35.94(-66.40,-5.48)	0.021
*** Adjusted Odds Ratio (AOD) = 95% Confidence Interval (CI)**		

9. Discussion

The study's overall QoL outcome was mean of 45.1 among MMC patients under 15 years of age on follow up at Neuroclinic at Tikur Ambessa and Zewditu memorial hospital neuro clinics.

Our study's overall QoL mean score (6.7) is lower than that of research conducted at German pediatric facilities and Zewditu Memorial Hospital. Participants in the Ethiopian study on quality of life and factors related to it in children with spina bifida had a median age of five years (interquartile range: three to six years) (6). Another study on 50 patients with MMC aged 8 to 16 was conducted at three pediatric centers in Germany. 56.4 (SD ± 14.7) was the overall PedsQL Generic Core score (7). One possible explanation for this could be the significantly lower economic position compared to the German study and the fact that most of the participants in our case were younger than seven years old.
Comparing our study's QoL ratings to other general score measures, we found that school functioning (33.43±18.56) and emotional functioning (36.5±16.85) had lower values. At 56.6±30.71, the mean physical functioning score was the highest, followed by social functioning (38.17±23.78). Physical functioning was much worse, according to a German study (total score: 41.8, SD = 20.1). Additionally, emotional functioning received the highest rating (total score: 63.9, SD = 14.5). The two research' differing sociodemographic, economic, and age groups could account for the discrepancy. (7)
In line with our study lowest quality of life scored for school functioning at Study In Zewditu Memorial Hospital (7).

In contrast to our findings, a Polish investigation on the quality of life of 52 patients with myelomeningocele revealed that emotional functioning was the most highly valued component (total score: 63.9, SD = 14.5) while physical functioning was noticeably worse (total score: 41.8, SD = 20.1) (5).
Our results' analysis indicates that presence of motor weakness is associated to a lower quality of life overall. This is consistent with a study on 80 children conducted at Aga Khan University (8). Our research reveals a strong correlation between household income and HRQoL, with higher-income households reporting higher HRQoL ratings. A study conducted at Zewditu Hospital in Ethiopia revealed a similar finding: households with higher incomes had higher HRQoL scores (7)

10. Limitation of the study

Because controls could not be examined, the cross-sectional design restricted the study's scope.
Only information from parents was collected; data from children was not compared.
Interviewer Bias

11. Conclusion

In conclusion, this study on pediatric quality of life score assessment is by far the first in the department of pediatrics. It has revealed that children with MMC typically have poor quality of life assessment scores. The results are useful for academics and clinicians who want to monitor and educate parents and kids using a general measure of quality of life.
Physical and social functioning scores are generally higher than academic and emotional functioning scores, even though the percentage of overall QoL results is low.

12. Recommendation

Based on the findings of the study. The recommendations are:
Creating multidisciplinary team involving Pediatrician,Neurosurgery,Dietician,physiotherapy and others

Further Prospective studies should be conducted to establish the difference of QoL between MMC patients and the general population.

Consideration of preparation of guidelines and protocols on monitoring and management of MMC patients' Qol despite the limitation of the study

13. **References**

1. Ball, M.A.Z., Clayton, D.B. Long-Term Quality of Life for Patients with Spina Bifida. Curr Bladder Dysfunct Rep (2024). https://doi.org/10.1007/s11884-024-00755-5
2. Oumer, M., Tazebew, A. & Silamsaw, M. Birth prevalence of neural tube defects and associated risk factors in Africa: a systematic review and meta-analysis. *BMC Pediatr* **21**, 190 (2021). https://doi.org/10.1186/s12887-021-02653-
3. Jimmy Ntimbani, Adrian Kelly, Patrick Lekgwara,Myelomeningocele - A literature review,Interdisciplinary Neurosurgery,Volume 19,2020,100502,ISSN 22147519,https://doi.org/10.1016/j.inat.2019.100502.(https://www.sciencedirect.com/science/article/pii/S2214751919301586)
4. Tesfay N, Hailu G, Habtetsion M, et alBirth prevalence and risk factors of neural tube defects in Ethiopia: a systematic review and meta-analysisBMJ Open 2023;13:e077685. doi: 10.1136/bmjopen-2023-077685
5. Rozensztrauch A, Iwańska M, Bagłaj M. The Quality of Life of Children with Myelomeningocele: A Cross-Sectional Preliminary Study. Int J Environ Res Public Health. 2021 Oct 13;18(20):10756. doi: 10.3390/ijerph182010756. PMID: 34682497; PMCID: PMC8535957
6. Surafeal Tafesse, Rocco Friebel, Yonas Mebratu Gebrecherkos, Tesfamariam Aklilu Betemariam, Tsegzeab Leake, Meskerem Aleka Kebede,Quality of Life and Its Associated Factors Among Children with Spina Bifida in Ethiopia: A Cross-Sectional Study to Inform Policy and Practice,World Neurosurgery,2024,ISSN 1878-8750,https://doi.org/10.1016/j.wneu.2024.06.028. (https://www.sciencedirect.com/science/article/pii/S1878875024009860).
7. Müller-Godeffroy E, Michael T, Poster M, Seidel U, Schwarke D, Thyen U. Self-reported health-related quality of life in children and adolescents with myelomeningocele. Dev Med Child Neurol. 2008 Jun;50(6):456-61. doi: 10.1111/j.1469-8749.2008.02054.x. Epub 2008 Mar 25. PMID: 18371093.

8. 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
9. Sahni M, Alsaleem M, Ohri A. Meningomyelocele. In: StatPearls. StatPearls Publishing, Treasure Island (FL); 2023. PMID: 30725644.
10. Buoro RS, Nogueira MP. QUALITY OF LIFE AND CHALLENGES OF FAMILY MEMBERS OF CHILDREN WITH MENINGOMYELOCELE. Acta Ortop Bras. 2020 Nov-Dec;28(6):291-295. doi: 10.1590/1413-785220202806237160. PMID: 33328785; PMCID: PMC7723383.
11. Bier JA, Prince A, Tremont M, Msall M. Medical, functional, and social determinants of health-related quality of life in individuals with myelomeningocele. Dev Med Child Neurol. 2005 Sep;47(9):609-12. PMID: 16138668.
12. Oncel MY, Ozdemir R, Kahilogulları G, Yurttutan S, Erdeve O, Dilmen U. The effect of surgery time on prognosis in newborns with meningomyelocele. J Korean Neurosurg Soc. 2012 Jun;51(6):359-62. doi: 10.3340/jkns.2012.51.6.359. Epub 2012 Jun 30. PMID: 22949965; PMCID: PMC3424176.
13. Sahni M, Alsaleem M, Ohri A. Meningomyelocele. [Updated 2023 Sep 4]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2024 Jan-. Available from: https://www.ncbi.nlm.nih.gov/books/NBK536959
14. Stevenson KL.Chiari Type II malformation:Past,Present and future.Neurosurg Focus.2004 Feb 15.16(2):ES
15. World Health Organization. Division of Mental Health and Prevention of Substance Abuse. (1997). WHOQOL : measuring quality of life. World Health Organization. https://iris.who.int/handle/10665/63482
16. Dorsher PT, McIntosh PM. Neurogenic bladder. Adv Urol. 2012;2012:816274. doi: 10.1155/2012/816274. Epub 2012 Feb 8. PMID: 22400020; PMCID: PMC3287034.
17. Varni JW, Seid M, Rode CA. The PedsQLTM:measurement model for the pediatric quality of life inventory. Med Care. 1999;37:126-139.

Annex I. Primary Caregiver's or patients Information sheet and Consent Form

Consent to participate in the study titled:

Patient or Parent reported quality of life of patients with MMC on follow up at TASH and ZMH,Neurosurgical clinic, Addis Ababa, Ethiopia**.**

Purpose of the study:

This study is being conducted to assess the QoL of patients with MMC under 15 years of age in follow up at TASH and ZMH, neuro clinic.

What participation involves:

If you consent to participate in this study, you will be interviewed for information regarding yours and the child's socio- demographic situation and health related information respectively. You will also be asked to fill out PedsQL^{TM} generic modules regarding the Child's condition.

Risks associated with participation:

There is no potential harm to you or the child associated with participating in this study.

Confidentiality:

Neither the child's nor your name will be recorded in the questionnaire. The information you provide will be kept confidential.

Right to not to participate or withdraw participation:

You have a full right not to participate in this research and you can withdraw your consent of participation at any point during the study. The child will continue to receive all medical services regardless of participation.

Benefits of participation:

If you consent to participate in this research, the information you provide about the child will be utilized for the possible provision of formal analysis regarding Quality of life patients with MMC and aid in hospital support services draw conclusion regarding topic in study

Primary caretaker's consent form

I have read and understood the information provided above. My questions have been answered. I, hereby, give my consent that the child's data can be used for the research. I confirm my agreement to let my child participate in the study with my signature below.

Name _____

Signature _____

Date _____

Contact information of the Primary Investigator:

Dr. Kefele Elias

Tel. **+251912627220**

Email kefelias@gmail.com

Department of pediatrics and child heath

Annex II. Study Questionnaire

Title of the Research – patient or Parent reported QoL of patients with MMC in follow up at TASH and ZMH, neuro clinic, Addis Ababa, Ethiopia.

Instructions

Please take your time to carefully complete the information below.

Code number _____ Date ____/___/___

Part I–Family/Primary caregivers' information

1. Relation to the child
   Mother___
   Father _____
   Other primary care giver _____
2. Age _____
3. Ethnicity - _____Religion - _____
4. Marital status/ family structure

   Married
   Divorced
   Widowed
   Single parent
   Separated

5. Parental educational status

Mother: -

Illiterate - _____

Completed primary education
Complete secondary education - _____
Complete college diploma - _____
Degree & above - _____

Father: -

Illiterate - _____
Completed primary education
Complete secondary education - _____
Complete college diploma - _____
Degree & above - _____

6. Parental occupation
   Mother: -
   House wife - _____
   Self-employee - ____
   Private employee - _____
   Government employee - _____
   Other - _____
   Father: -
   Unemployed - _____
   Self-employee - _____
   Private employee - _____
   Government employee - _____
   Other - _____
7. Family monthly income
   <5000 birr - _____
   5000- 15,000 birr - _____
   >15,000 birr - _____

Part II–information on the child (from Parents / care givers or patient it self)

8. Gestational age at birth A<37Week B=>37Week - _____
9. Age
10. Sex A =Male - B= Female - _____
11. Mode of diagnosis A=Clinical_____ B=Imaging_____
12. School grade _____
13. Comorbidities _____

Annex III – PedsQL ™4.0 Generic scoring

Parent report for children on Generic QoL

Directions: - on the following page is a list of things that might be a problem to your child; please tell us how much of a problem has it been to your child in the past 1 month.

0 =it's never a problem 1 =it's almost never a problem 2 =it's sometimes a problem 3=it's often a problem 4= it's almost always a problem

Physical functioning	**Never**	**Almost never**	**sometimes**	**Often**	**Almost always**
Walking more than one block	0	1	2	3	4
Running	0	1	2	3	4
Participating in sports & exercise	0	1	2	3	4
Lifting something heavy	0	1	2	3	4
Taking bath or shower by him self	0	1	2	3	4
Having hurts or aches	0	1	2	3	4
Low energy level	0	1	2	3	4

Emotional functioning	**Never**	**Almost never**	**sometimes**	**Often**	**Almost always**
Feeling afraid or scared	0	1	2	3	4
Feeling sad or blue	0	1	2	3	4
Feeling angry	0	1	2	3	4
Trouble with sleeping	0	1	2	3	4
Worrying about what will happen to him/her	0	1	2	3	4

Social functioning	**Never**	**Almost never**	**sometimes**	**Often**	**Almost always**
Getting along with other children	0	1	2	3	4
Other kids not wanting to be his/her friend	0	1	2	3	4
Getting teased by other children	0	1	2	3	4
Not able to do things that other children his/her age can do	0	1	2	3	4
Keeping up when playing with other children	0	1	2	3	4

School functioning	Never	Almost never	sometimes	Often	Almost always
Paying attention in class	0	1	2	3	4
Forgetting things	0	1	2	3	4
Keeping up with school work	0	1	2	3	4
Missing school because not feeling well	0	1	2	3	4
Missing school to go to hospital	0	1	2	3	4

Study Specific Questionnaire

1. Age at diagnosis…..

2. Site of lesion: A= above lumbosacral area B=At lumbosacral area

3. Is your child operated A-Yes B-No

4 In question number 3 if operated age during operation

5. Do you have renal clinic follow up? A-Yes, B-No

6. Presence of hydrocephalus A=Yes B=No C=No information

7. Presence of neurogenic bladder A=Yes B=No C=No information

8. Attending health education about your illness during follow up A=yes B=No

9. Bowel incontinence A=Yes B=No

10. Urinary incontinence A=Yes B=No

11. Post OP CSF leak A=Present B=Not present

12. Lower motor weakness present during time of diagnosis

A=YES B=NO

13. Has the child's illness forced the parent to quit their job A=Yes B=No

14. If yes to question number 13 which parent A=Mother B=father