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Socio-economic determinants and mortality patterns among children with spina bifida at Ruharo Mission Hospital, Western Uganda: A retrospective cross-sectional study.

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Abstract

Background
Spina Bifida (SB) is a significant cause of childhood morbidity and mortality in low-resource settings like Uganda. While clinical management is crucial, the role of socioeconomic determinants on survival outcomes remains underexplored. This study investigates the association between socioeconomic factors and mortality patterns among children with SB in Western Uganda.

Methods
A retrospective study design with a mixed-methods approach was conducted, a review of 152 medical records of children with SB (2013–2023) with qualitative focus group discussions involving 20 caregivers and 15 health workers. Quantitative data were analyzed using descriptive statistics, Firth logistic regression, and Kaplan-Meier survival analysis. Qualitative data were analysed thematically.

Results
The study revealed a high mortality rate of 65.1% (99/152). Multivariate analysis identified key socioeconomic determinants significantly associated with increased mortality: caregiver unemployment (β=1.53, OR=4.62, p=0.045), use of unprotected water sources (β=2.18, OR=8.83, p<0.001), and living 5-10 km from the health facility (β=4.42, OR=83.7, p=0.007). Most deaths (49.5%) occurred in infancy (1-11 months). Survival analysis showed a median survival time of 3-4 years, with infections being the leading cause of early death. Qualitative findings from caregivers and health workers highlighted family financial constraints, stigma, transportation barriers, and health system gaps (e.g., shortages of supplies and specialists) as critical challenges.

Conclusion
Mortality among children with Spina Bifida in Western Uganda is high and is profoundly influenced by modifiable socioeconomic determinants. Caregiver unemployment, poor water and sanitation, and geographical barriers to healthcare are significant predictors of mortality among children with SB.

Recommendations
Effective interventions must extend beyond clinical care to include socioeconomic support, inclusive livelihood interventions, such as financial protection schemes, income-generating activities, improved WASH infrastructure, decentralization of services, and community sensitization to reduce stigma. A multi-sectoral approach is essential to improve survival and quality of life for this vulnerable population of children with SB.

Keywords: *Spina Bifida, Mortality, Socioeconomic Determinants, Uganda, Children, Health Disparities.*
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Background

Spina bifida (SB) is a neural tube defect (NTD) that occurs during early embryonic development when the neural tube fails to close properly (US-CDC, 2023). The neural tube, which gives rise to the brain, spinal cord, and supporting structures, normally closes by the 28th day after conception (Saba et al., 2023). Globally, NTDs are the second most common congenital anomalies after cardiac malformations, accounting for more than 300,000 new cases annually (Botto et al., 2005).

Children born with SB often experience lifelong functional challenges, including paralysis, impaired mobility, bowel and bladder dysfunction, shunt complications, and tethered cord syndrome (Hassan et al., 2022; NINDS, 2024). These health complications place a considerable burden not only on affected individuals but also on families, communities, and healthcare systems, particularly in low- and middle-income countries (LMICs) (Zaganjor et al., 2016).

In Uganda, SB remains a significant public health concern, with an estimated birth incidence of approximately 1 in 1,000, translating to about 1,400 new cases annually (Warf et al., 2011). The condition contributes to long-term disability, necessitating lifelong rehabilitation and specialized medical care. Families often face high economic costs, with annual expenditures for surgical and rehabilitative services exceeding six million Uganda shillings per child, excluding indirect costs such as transport, caregiver time, and lost income (CURE International, 2024). These challenges are compounded by the limited healthcare infrastructure, with only four facilities in Uganda offering SB care and just one equipped with adequate human resources and technology (Warf et al., 2011).

Socioeconomic factors, such as poverty, limited access to health services, and inadequate prenatal care, play a critical role in influencing both access to treatment and survival outcomes for children with SB. Families with limited resources face barriers to timely care, exacerbating morbidity and mortality (Ay & Akkoyun, 2024). Despite medical advancements that have improved survival rates, there is limited research examining the influence of socioeconomic determinants on SB outcomes in sub-Saharan Africa.

This study, therefore, seeks to address this gap by exploring the socioeconomic determinants of mortality among children with SB in Western Uganda. By identifying these factors, the research aims to inform evidence-based, community-oriented interventions that extend beyond clinical care and address the broader social and economic barriers to survival and quality of life.

Methodology

Area of the study

The study was conducted in Western Uganda, focusing on Ruharo Mission Hospital and its surrounding communities. Western Uganda is geographically diverse, consisting of mountains, hills, and plateaus within the Albertine Rift Valley. The region experiences a tropical climate with average temperatures ranging from 18°C to 28°C and two rainy seasons (March–May and September–November). These conditions enhance agricultural productivity but can hinder transportation and healthcare access, particularly in rural areas. The study ran from June 2025 to August 2025.

Ruharo Mission Hospital, situated in Mbarara City, about 265 km southwest of Kampala, serves a wide catchment area including Mbarara, Bushenyi, Sheema, and Kiruhura districts. The area is predominantly rural, with agriculture as the main economic activity. However, poverty, limited healthcare access, and educational challenges persist, underscoring the importance of examining socioeconomic determinants of mortality among children with spina bifida in this region.

Research design

Quantitatively, a retrospective descriptive design, in which a mixed-methods approach was adopted, was used to review medical records of pediatric patients with spina bifida who died at Ruharo Mission Hospital between 2013 and 2023. Qualitatively, a phenomenological design was employed to capture the lived experiences of caregivers and health workers, providing context to the quantitative findings.

Study population

The study population consisted of pediatric patients diagnosed with spina bifida who received care at Ruharo Mission Hospital but subsequently died. Caregivers of these children and healthcare workers involved in their management were also included.

Population characteristics

Age: Children aged 0–18 years.
Diagnosis: Clinically confirmed spina bifida cases.
Geography: Patients drawn from Western Uganda within the hospital's catchment area.

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Socioeconomic diversity: Families representing varied economic backgrounds.
Healthcare access: Patients managed at Ruharo Mission Hospital or through outreach programs.

Sampling procedures

Sampling technique

Random sampling was used to select records, ensuring representation across socioeconomic and geographic strata.
Sample Size Determination
Sample size was calculated using the Cochran formula

$$n_0 = \frac{Z^2 \cdot p \cdot (1-p)}{e^2}$$

where Z = 1.96 (95% confidence), p = 0.5, and e = 0.05, yielding n_0 = 384. For a finite population of 50, the adjusted sample size was 44. However, medical records identified 152 eligible cases, and all were included to increase power and minimize sampling error
Qualitatively, 20 caregivers participated in focus group discussions, and 15 healthcare workers (nurses, therapists, and social workers) participated as key informants.

Inclusion criteria

- Complete medical records of pediatric patients (0–18 years) diagnosed with spina bifida who received services at Ruharo Mission Hospital between 2013–2023.
- Complete records with demographic, clinical, and socioeconomic data.
- Caregivers who provided informed consent.

Exclusion criteria

- Incomplete records lacking mortality or socioeconomic data.
- Cases with unrelated major illnesses.

Data collection

Quantitative data were extracted from medical records using structured forms that captured demographics, clinical details, socioeconomic factors, and outcomes.
Qualitative data: Collected through semi-structured interviews and focus group discussions guided by interview protocols. These explored healthcare access, affordability, and socioeconomic challenges.

Bias

Training data collectors, using standardized case definitions, cross-checking with hospital records, and double-entering data were done to reduce information bias.

Data quality control

Reliability was ensured through the training of research assistants and close supervision during data collection. Validity was strengthened through the use of standardized tools, pilot testing, and triangulation of methods.

Data analysis

Quantitative data analysis was performed using Stata software version 17. Univariate statistics described the study population; bivariate tests (chi-square and t-tests) examined associations between socioeconomic determinants and mortality. Multivariate analysis, including logistic regression and Cox proportional hazards models, was applied to identify predictors while controlling for confounders. A p-value <0.05 was considered significant.
Qualitative data were transcribed and analyzed thematically. Codes were generated, categorized, and developed into themes reflecting healthcare access, affordability, and socioeconomic barriers. Integration of qualitative and quantitative findings enhanced interpretation.

Ethical considerations

Ethical approval was obtained from the Bishop Stuart University Research and Ethics Committee (REC) on 12th June 2025, with approval number BSU-REC-2025-528 and permission from Ruharo Mission Hospital. Written informed consent was secured from caregivers. Confidentiality was maintained by replacing personal identifiers with codes and securely storing data. For deceased patients, a waiver of consent was granted by the REC for medical record review.

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Results

Table 1: Descriptive statistics of children with spina bifida and their caregivers (N = 152)

Variable	N	Mean	Std. Dev.	Min	Max
Caregiver Age (years)	152	30.1	9.36	17	73
Household Size (members)	152	5.6	2.70	1	18
Distance to Facility	152	1.72	1.12	1	4

Key for Distance is coded as: 1 = more than 10km, 2 = 1-5km, 3 = less than 1km, 4 = 5-10km

The mean age of caregivers was 30.1 years (SD = 9.36), with a range of 17 to 73 years. Household sizes varied widely, with an average of 5.6 members (SD = 2.70), suggesting potential resource constraints in caregiving environments. The average distance to the health facility was 1.72 (SD = 1.12) on a scale of 1 to 4, indicating that most caregivers lived within a 10 km radius of the hospital, although some faced longer travel distances.

Table 2: Mortality status of children with spina bifida (N = 152)

Mortality Status	Frequency	Percentage (%)
Alive	53	34.9
Died	99	65.1
Total	152	100.0

Table 2 shows the mortality status of children with spina bifida in the study sample. Of the 152 children included, 99 (65.1%) had died, while only 53 (34.9%) were alive. These findings demonstrate that mortality among children with spina bifida is high in this population.

The results suggest that the survival chances of children with spina bifida are relatively low in this setting, likely reflecting challenges such as delayed diagnosis, limited access to surgical interventions and rehabilitation, socioeconomic constraints, and long distances to health facilities.

Table 3: Caregiver educational level and household size by mortality status

Variable	Alive (n=53)	Died (n=99)	Total (n=152)	Statistical test
Educational level				Chi-square test
Primary	31 (58.5%)	41 (41.4%)	72 (47.4%)	
Secondary	17 (32.1%)	46 (46.5%)	63 (41.4%)	
Higher	5 (9.4%)	12 (12.1%)	17 (11.2%)	
Household size (mean ± SD)	5.0 ± 2.3	5.8 ± 2.8	5.6 ± 2.7	t (150) = –1.78, p=0.077

Caregiver education and mortality

Table 3 presents the distribution of caregiver education levels by child mortality status. Among children who survived, 58.5% had caregivers with no formal education, while 32.1% had primary education. In contrast, among those who died, 46.5% had caregivers with primary education. This suggests that caregiver education alone may not be protective against mortality, and other socioeconomic factors may mediate its impact.

Household size and mortality

A two-sample t-test comparing household size between survivors and deceased children showed a mean difference of 0.81 (t = -1.78, p = 0.077). Although not statistically significant, the trend suggests that larger households may be associated with increased mortality risk, possibly due to resource constraints in these families.

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Table 4: Comparison of the caregiver age and mortality status

Group	N	Mean Age	Std. Dev.	95% CI
Alive	53	28.1	9.02	[25.61, 30.58]
Died	99	31.2	9.42	[29.27, 33.03]
Total	152	30.1	9.36	[28.58, 31.59]
Difference		-3.06		[-6.18, 0.06]
p-value				0.055

Table 4: The average caregiver age was slightly higher among children who died (31.2 years) compared to those who survived (28.1 years). The difference of 3.06 years was marginally significant (p = 0.055), which suggests a possible trend. Older caregivers may face more health or financial challenges, or may be caring for multiple dependents, which could affect their ability to provide intensive care. This can also be attributed to the cases in which some children are neglected and left with their grandparents.

Table 5: Association between caregiver employment status and mortality status of children with spina bifida (N = 152)

Employment Status	Alive (n=53)	Died (n=99)	Total (n=152)	χ^2 (df)	p-value
Employed (1)	44 (83.0%)	56 (56.6%)	100 (65.8%)		
Unemployed (2)	9 (17.0%)	43 (43.4%)	52 (34.2%)		
Total	53 (100%)	99 (100%)	152 (100%)	10.73 (1)	0.001 **

Table 5 presents the association between caregiver employment status and mortality among children with spina bifida. The chi-square test revealed a significant association, χ^2 (1) = 10.73, p = 0.001. Children whose caregivers were unemployed experienced a higher mortality rate (43.4%) compared to those with employed caregivers (17.0%). This finding suggests that caregiver employment is protective, likely due to improved financial stability, access to resources, access to healthcare, and caregiving capacity.

Table 6: Cox Proportional Hazards Regression of Socioeconomic determinants associated with mortality among children with Spina Bifida (n=152). Time at risk was calculated as _t = survival time/365.25 (in years)

Variable	Category	HR	Std Error	Z	P-value	95% CI
Primary Caregiver	Father (2)	0.556	0.405	-0.81	0.420	0.133–2.315
	Grandmother/Relative (3)	1.147	0.584	0.27	0.788	0.423–3.111
Educational Level	Primary (2)	1.100	0.249	0.42	0.674	0.706–1.714
	Secondary+ (3)	0.591	0.223	-1.40	0.163	0.282–1.237
Employment Status	Employed (2)	1.836	0.430	2.59	0.009	1.160–2.906
Water Source	Piped water (2)	0.563	0.217	-1.49	0.135	0.265–1.197
	Borehole (3)	0.443	0.333	-1.08	0.278	0.102–1.930
	Valley dams/unprotected well (4)	1.691	0.389	2.28	0.022	1.077–2.655
Distance to Facility	1–5 km (2)	2.802	0.990	2.92	0.004	1.402–5.600
	<1 km (3)	2.750	0.918	3.03	0.002	1.430–5.290
	5–10 km (4)	1.947	0.540	2.40	0.016	1.130–3.353

Key: HR = Hazard Ratio; Std Error = Standard Error; Z = Z-value; CI = Confidence Interval.
Event: _d = fail; Time at risk: _t = survival time/365.25 (years).
Reference categories: Primary caregiver = Mother (1); Educational Level = No Education (1); Employment Status = Unemployed (1); Water Source = River/Lake (1); Distance to Facility = >10 km (1).

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The Cox regression analysis results revealed several important associations between socioeconomic factors and mortality among children with Spina Bifida. Employment status emerged as a significant predictor, with children from unemployed households facing a markedly higher risk of death (HR = 1.84, p = 0.009), underscoring the role of economic vulnerability in shaping health outcomes.

Water sources also showed a notable effect in the children from households relying on valley dams and unprotected wells had significantly increased mortality risk (HR = 1.69, p = 0.022) compared to those using rivers or lakes, likely reflecting the impact of unsafe water on infection and hygiene-related complications.

Distance to health facility was consistently associated with elevated risk—children living 1–5 km (HR = 2.80, p = 0.004), less than 1 km (HR = 2.75, p = 0.002), and 5–10 km (HR = 1.95, p = 0.016) from a facility all had significantly higher hazards compared to those living more than 10 km away. This counterintuitive pattern may reflect reverse causality, where families closer to facilities are more likely to bring in severely ill children, or where health facilities are located in areas with higher disease burden. Other variables, including primary caregiver and educational level, did not show statistically significant associations, though trends suggest that caregiver identity and education may still influence survival indirectly.

Overall, the model was statistically significant (LR χ^2 = 48.23, p < 0.001), indicating that these socioeconomic factors collectively contribute meaningfully to mortality risk in this population.

Table 7: Firth logistic regression predicting mortality among children with spina bifida (N = 152)

Socio-economic Predictor	Category	Coefficient (β)	Std. Error	z-value	p-value	95% Confidence Interval
Educational Level	Primary vs. None	0.38	0.51	0.74	0.462	[-0.63, 1.38]
	Secondary+ vs. None	-0.71	1.08	-0.66	0.509	[-2.83, 1.40]
Household Size	Continuous	0.15	0.10	1.47	0.143	[-0.05, 0.35]
Employment Status	Unemployed vs. Employed	1.53	0.76	2.00	0.045	[0.03, 3.02]
Water Source	Piped vs. River/Lake	-1.10	0.79	-1.40	0.162	[-2.65, 0.44]
	Borehole vs. River/Lake	-1.39	1.17	-1.19	0.235	[-3.70, 0.91]
	Unprotected Wells/Dams vs. River/Lake	2.18	0.57	3.81	< 0.001	[1.06, 3.31]
Sanitation Facility	Pit Latrine vs. None	-1.97	1.14	-1.73	0.084	[-4.21, 0.27]
	Flush Toilet vs. None	-0.24	1.72	-0.14	0.891	[-3.61, 3.14]
Distance to Facility	1–5 km vs. >10 km	2.85	1.00	2.84	0.004	[0.89, 4.81]
	10 km	2.12	1.01	2.09	0.037	[0.13, 4.10]
	5–10 km vs. >10 km	4.42	1.63	2.71	0.007	[1.23, 7.60]
Constant		-1.69	0.74	-2.28	0.023	[-3.15, -0.24]

Model Fit: (Wald $\chi^2(12) = 37.19$, p = 0.0002 Penalized Log Likelihood) 45.84

Reference categories: No education, Employed, River/Lake water source, No sanitation facility, >10 km from facility.

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Firth, logistic regression was used to assess socioeconomic determinants of mortality among children with spina bifida (Table 7).

Caregiver education showed no significant association with child mortality: primary education (β = 0.38, OR = 1.46, 95% CI: 0.53–4.52, p = 0.462) and secondary+ education (β = –0.71, OR = 0.42, 95% CI: 0.04–4.85, p = 0.509). Household size slightly increased the odds of mortality (β = 0.15, OR = 1.20, 95% CI: 0.97–1.49), but this was not significant (p = 0.143).

Employment status was significant: children from unemployed households had higher odds/risk of mortality compared to employed (β = 1.53, OR = 4.62, 95% CI: 1.03–20.56, p = 0.045). In this case, employment status is an important protective factor as employed caregivers likely had better financial stability for transport, access, and timely access to treatment and nutrition.

Water source mattered: piped water (β = –1.10, OR = 0.33, p = 0.162) and boreholes (β = –1.39, OR = 0.25, p = 0.235) showed lower, but non-significant odds, while unprotected wells/dams strongly increased mortality (β = 2.18, OR = 8.83, 95% CI: 2.88–28.36, p < 0.001). It can therefore be appreciated that Children who were relying on unsafe water sources (unprotected wells/dams) had much higher odds of mortality (about 8.8 times greater) compared to those using river/lake water. Piped or borehole water showed a protective trend, but this was not statistically significant in this sample.

Sanitation facilities had no significant effect: pit latrine (β = –1.97, OR = 0.14, p = 0.084) and flush toilet (β = –0.24, OR = 0.79, p = 0.891). Having a pit latrine was associated with lower odds of mortality, though only marginally significant. Flush toilets showed no effect, perhaps due to very few households having them.

Distance to health facility was significant: living 1–5 km (β = 2.85, OR = 17.3, p = 0.004), <1 km (β = 2.12, OR = 8.34, p = 0.028), and 5–10 km (β = 4.42, OR = 83.7, p = 0.007) all showed markedly higher odds compared to >10 km.

The constant was significant (β = –1.69, p = 0.023), and the overall model fit was good (Wald $\chi^2(12) = 37.19$, p = 0.0002).

Table 8: Cross-tabulation of Sex and Mortality Status

Sex	Died (n, %)	Total (n)
Male	53 (69.7%)	76
Female	46 (60.5%)	76
Total	99 (65.1%)	152

Table 8 shows the relationship between child sex and mortality status. Among male children, 53 (69.7%) had died compared to 46 (60.5%) of female children. Conversely, 23 (30.3%) of males and 30 (39.5%) of females were alive at the time of data collection. Overall, mortality was higher among male children compared to females, although the difference between sexes was modest.

Table 9: Summary of age at death among children with spina bifida (N = 99)

Variable	N	Mean	Std. Deviation	Minimum	Maximum
Age at death (years)	99	2.56	3.91	0	16.8

Among the 99 children who died, the mean age at death was 2.56 years (SD = 3.91), with a range from birth (0 years) to 16.8 years. This indicates that most deaths occurred in early childhood.

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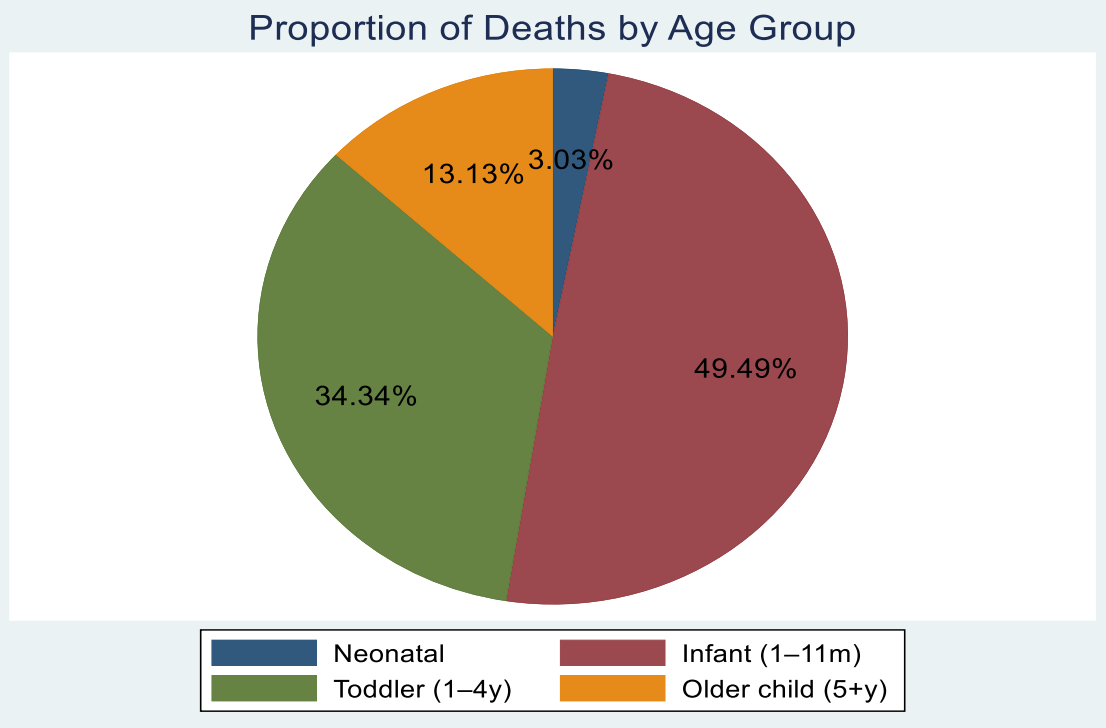
Figure 1: Pie chart showing age group distribution at death among children with spina bifida (N = 99)



Out of the 99 deaths among children with spina bifida, nearly half, 49 (49.5%), occurred during infancy (1–11 months). A further 34 (34.3%) of deaths were recorded in the toddler age group (1–4 years), while 13 (13.1%) occurred among older children aged 5 years and above. 3 (3%) of deaths occurred during the neonatal period (first 28 days of life). These findings indicate that most of the mortality, i.e., 86.86% in this population, occurred within the first 05 years of life, with infancy being the most vulnerable period.

Figure 2: Deaths by Year of Death (2013–2023)

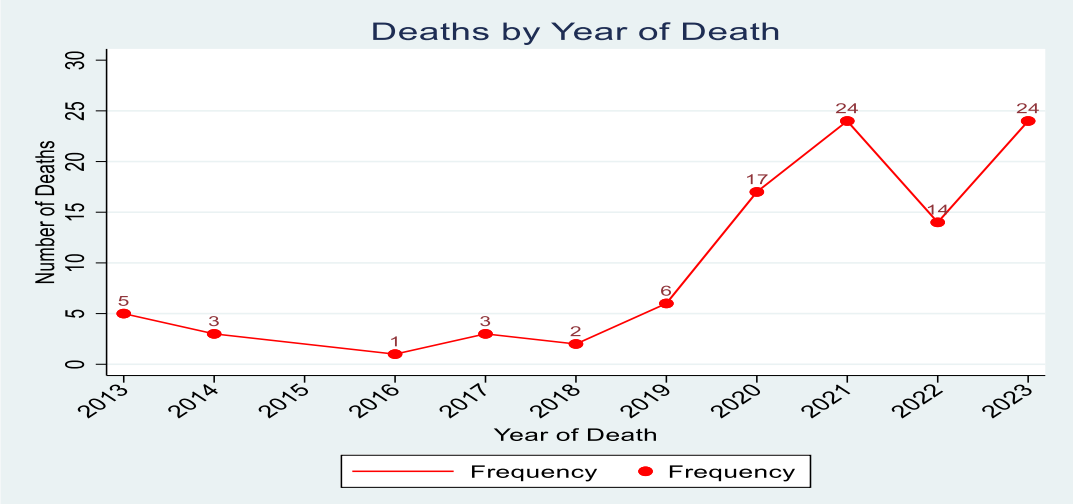


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Figure 2 shows the temporal trend of deaths recorded between 2013 and 2023. Overall, the number of deaths fluctuated at low levels between 2013 and 2018, with annual counts ranging from 1 to 5. From 2019 onwards, there was a sharp increase in deaths, rising from 6 in 2019 to 17 in 2020, and peaking at 24 deaths in both 2021 and 2023. Although there was a decline in 2022 (14 deaths), the general trend demonstrates a substantial rise in mortality over the study period, particularly from 2019 onwards.

This pattern suggests that while mortality was relatively stable and low in earlier years, a notable escalation occurred in the later years, which may reflect changes in risk factors, health care access barriers, e.g., those associated with COVID-19, social determinants, or also the reporting practices during this period.

Figure 3: Temporal Trends in Causes of Death (2013–2023)

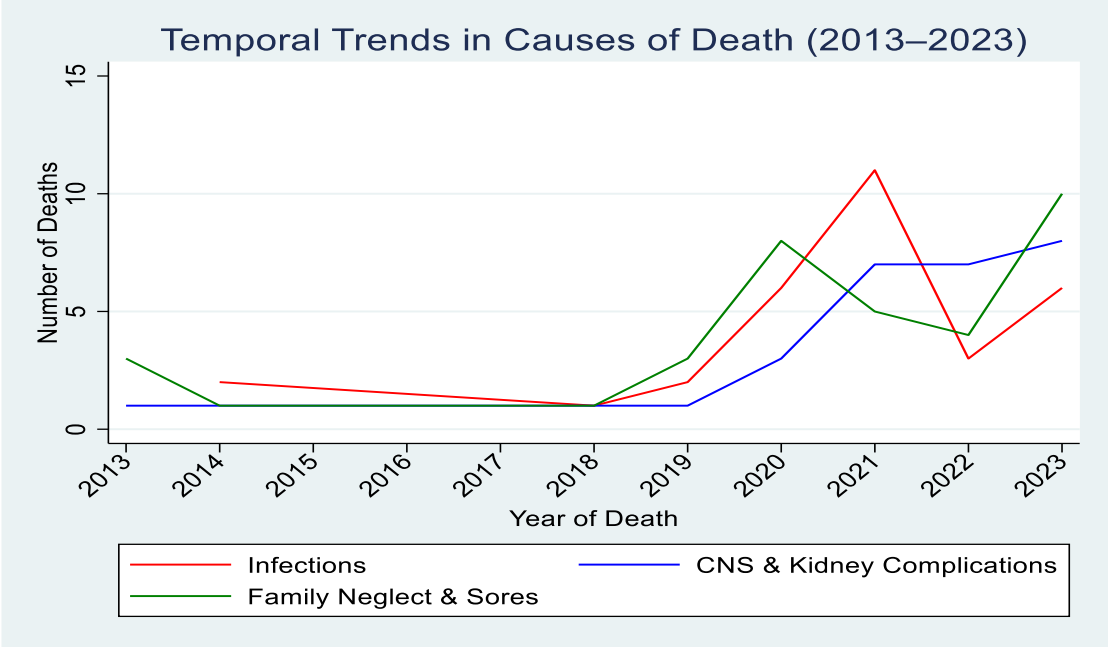

Figure 3 shows the temporal distribution of major causes of death among the study population between 2013 and 2023. Deaths due to infections showed a fluctuating trend, with a noticeable peak in 2021 before declining and slightly rising again in 2023. Deaths related to CNS and kidney complications remained relatively low and stable up to 2019, after which they increased gradually and reached their highest levels in 2022–2023. In contrast, deaths attributed to family neglect and sores remained low until 2018, followed by a steady rise that peaked in 2023. Overall, the findings indicate a shift in the dominant causes of mortality over time, with infections being more prominent in the earlier years, while complications and neglect-related causes have become increasingly significant in recent years.

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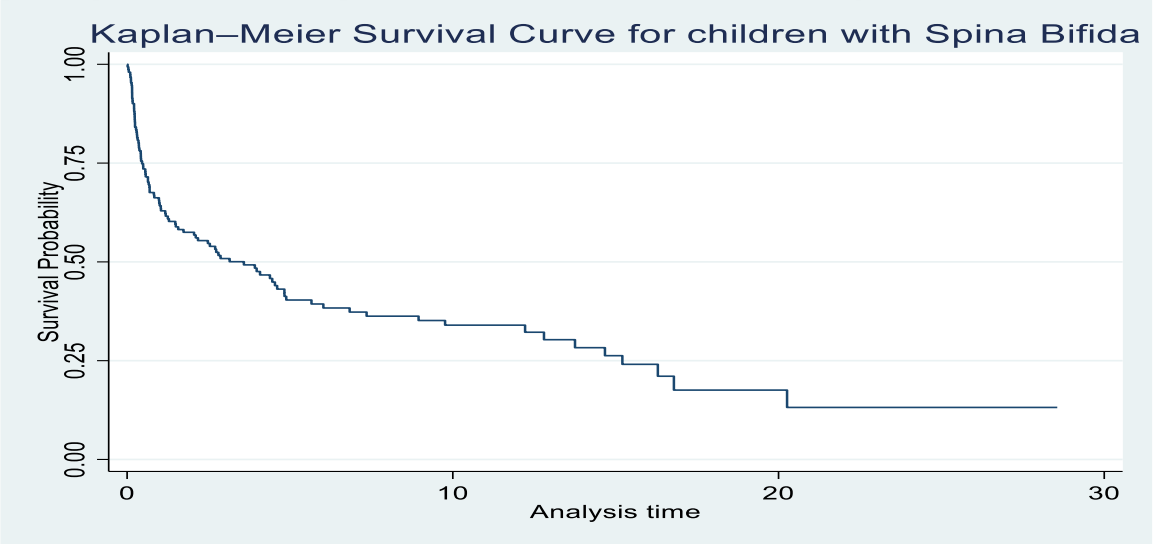
Fig 4: Kaplan Meier showing the survival curve for children with Spina Bifida

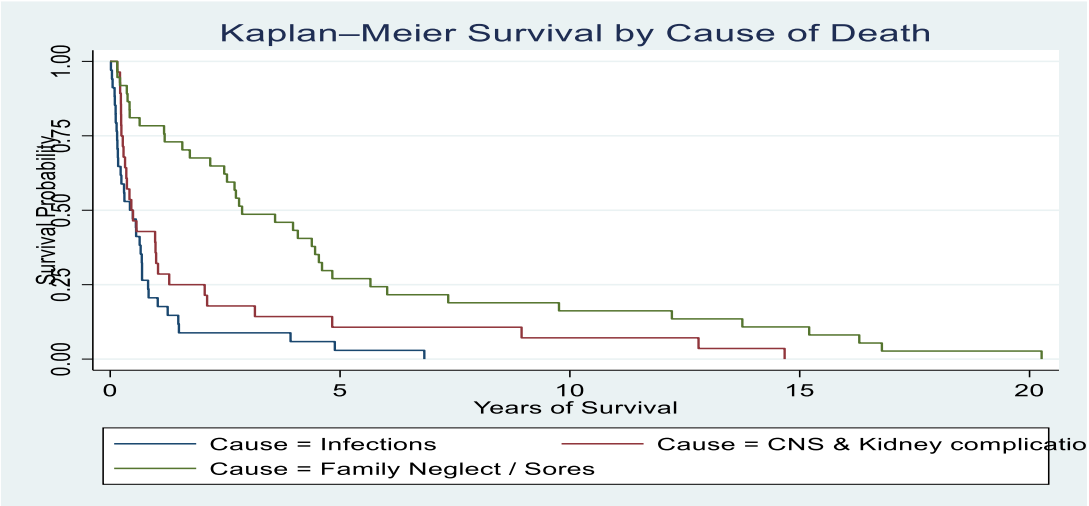


A Kaplan–Meier survival analysis was performed to estimate survival probabilities among children with Spina Bifida. The survival curve (Figure 6) demonstrated a steep decline in survival during the early years of life, indicating high mortality soon after diagnosis or birth. The median survival time was approximately 3–4 years.

By the end of the first year, survival probability had declined markedly, and by 10 years of follow-up, only about one-third (≈30%) of children were still alive. At 20 years, the survival probability was further reduced to approximately 15–20%.

These findings suggest that although mortality is highest in the first few years of life, a subset of children who survive this early critical period are likely to live into adolescence and early adulthood. This pattern highlights both the vulnerability of children with Spina Bifida in early life and the potential for improved outcomes with timely interventions and long-term care.

Fig 5: Kaplan Meier showing the survival by cause of death among children with Spina Bifida



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The Kaplan–Meier survival analysis demonstrated distinct differences in survival probabilities among children with Spina Bifida according to the underlying cause of death. Children who died due to infections experienced the shortest survival times, with their probability of survival dropping steeply within the first few years of life. Those with CNS and kidney complications also showed reduced survival, though their curve declined at a relatively slower pace compared to infections. In contrast, children whose deaths were attributed to family neglect and sores survived longer on average, with their survival curve remaining higher for a prolonged period before gradually declining.

The log-rank test confirmed that these differences were statistically significant ($\chi^2(2) = 26.57$, $p < 0.001$). These findings highlight that infections are the most detrimental to early survival, followed by CNS and kidney complications, while neglect and sores were associated with longer but eventually reduced survival.

Insights were obtained from focus group discussions with mothers/caregivers and key informant interviews with health workers. Thematic analysis revealed several socio-economic challenges contributing to mortality, alongside recommendations for intervention.

Table 9: Themes from caregivers and health workers on socio-economic determinants of mortality

Theme	Evidence from Participants	Caregivers' quotes during the interviews	Policy/Intervention Implication
Financial Constraints	Caregivers struggled with the cost of transport, medical bills, and nutrition.	*"I sometimes have to choose between buying food for the family and taking my child for a review at the hospital."* (Mother, FGD) *"My husband doesn't want to be involved in the care of the child, as he says the child is the cause of all poverty at home, and he even wishes the demise of the child.* *We have had family debts ever since this child came in, since the child started getting treatment, we spent a lot"*(Mother, FGD)	Subsidized treatment and financial support schemes for vulnerable families.
Access to Health Services	Long distances to Ruharo Mission Hospital and high transport costs limited follow-up.	*"We walk very long distances or spend a lot of money to reach the hospital. Sometimes we just fail to come."* (Mother, FGD) *"I didn't know about folic acid, not until I got a baby with spina bifida."*	There is a need to consider establishing satellite clinics or integrating services into lower-level health facilities.
Stigma and Community Attitudes	Mothers reported discrimination and neglect of affected children. The mothers reported being abandoned by their spouses, extended families, and the general community.	*"People in the community say we are cursed, and sometimes they tell us to just leave the child to die."* (Mother, FGD) *"My husband neglected me with the child, because the child has spina bifida, he went ahead and said, after all, I have"*	Community sensitization interventions to reduce stigma are highly needed, and to strengthen psychosocial support systems.

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Sanitation and Hygiene	Difficulty managing sores and infections due to poor sanitation facilities.	*"At home, we don't have proper toilets. My child gets sores that don't heal."* (Mother, FGD)	It is important to consider interventions aimed at improving community WASH (water, sanitation, hygiene) infrastructure and training caregivers in home-based care.
Health System Gaps	Health workers cited shortages of supplies and a lack of specialized staff.	*"Sometimes we lack catheters and antibiotics, yet these are lifesaving for these children."* (Health Worker, KII) *"The region has, I think, only 01 neurosurgeon, which means that the neurosurgeon to population ratio is disproportionate, children are not operated on in time, and even equipment and theatre spaces are limited."*	The government and partners need to ensure a consistent supply of medical consumables to train more specialists.
Need for Counseling and Social Support	Caregivers expressed a need for peer and psychosocial support.	*"When I meet other mothers with the same problem, I feel I am not alone."* (Mother, FGD)	Strengthen caregiver support groups and integrate counselling into routine care

The findings demonstrate that multiple socio-economic determinants directly contribute to mortality among children with Spina Bifida.

Financial barriers were a recurrent theme, with mothers reporting that competing needs often forced them to delay or skip hospital visits. Distance to Ruharo Mission Hospital further compounded these challenges, as families often lacked transport. One caregiver narrated: *"You see, we travel very long distances or spend a lot of money to reach the hospital. Sometimes we just fail to come."*

Stigma and negative cultural beliefs also emerged strongly, with mothers being blamed or shamed for their child's condition. A mother explained: *"People in the community say we are cursed, and sometimes they tell us to just leave the child to die."* Such attitudes not only isolate caregivers but also discourage timely health-seeking.

Environmental challenges, such as poor sanitation, were linked to infections and sores that worsened health outcomes. Caregivers described struggling with wound care at home, often in settings without adequate facilities. Similarly, health workers highlighted systemic gaps, including a lack of essential supplies like catheters and antibiotics, as well as insufficient numbers of trained personnel.

Despite these challenges, participants identified possible interventions. Caregivers expressed that counseling and peer support groups were sources of resilience and could help families cope better. Health workers recommended strengthening health systems through supply-chain improvements and expanding specialized care to peripheral facilities.

Discussion

The findings of this study resonate with evidence from other LMICs, where poverty, poor access to care, and stigma drive high mortality among children with SB. For instance, studies in Nigeria and Ethiopia revealed similar mortality rates exceeding 60%, with socioeconomic disparities as the primary predictor (Komolafe et al., 2017; Oumer et al., 2020). In contrast, high-income countries have reported dramatic improvements in survival, with most children living into adulthood. This gap underscores the inequities in health systems and the role of social determinants in survival outcomes.

The association between caregiver unemployment and mortality reflects the importance of household economic stability. Similar findings were reported in Turkey, where low parental education and income restricted access to physiotherapy and rehabilitation (Ayl et al., 2024). The significant role of unsafe water sources further highlights how WASH interventions could indirectly reduce SB-related mortality by preventing infections and wound complications. Stigma remains an underexplored but critical factor—community beliefs that children with SB

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are cursed directly affect care-seeking and psychosocial wellbeing.

This study contributes new evidence from Western Uganda, where limited literature exists on socioeconomic determinants of SB mortality. It underscores the need for disability-inclusive policies, long-term and integrated healthcare with social protection, education, and community mobilization.

This study demonstrates that mortality among children with SB in Western Uganda is significantly shaped by socioeconomic determinants. The findings align with literature from LMICs showing that poverty, poor health infrastructure, and stigma exacerbate mortality risks. Caregiver unemployment was strongly associated with child mortality, reflecting financial instability as a barrier to timely care (Cooper et al., 2017). Reliance on unsafe water sources was associated with higher mortality, indicating the impact of environmental determinants. Despite clinical advancements, limited access to specialized neurosurgical and rehabilitative services continues to hinder outcomes. Community stigma further marginalizes families, discouraging health-seeking behavior.

The results underscore the urgent need for holistic public health interventions that integrate medical, social, and economic strategies. Strengthening community health systems, expanding access to rehabilitation, and implementing social protection schemes for vulnerable families could improve survival outcomes.

Generalizability

The findings of this study provide important insights into the socioeconomic determinants of mortality among children with Spina Bifida in a low-resource setting. However, generalisability is limited by the study's retrospective design and its focus on a single tertiary facility, Ruharo Mission Hospital. While the hospital serves a broad catchment area and includes children from diverse socioeconomic backgrounds, the sample may not fully represent children with Spina Bifida who were managed in other facilities in other regions. Additionally, regional variations in health infrastructure, cultural beliefs, and caregiving practices across Uganda and sub-Saharan Africa may influence the applicability of these results. Nevertheless, the integration of quantitative and qualitative methods enhances the depth and contextual relevance of the findings, supporting their transferability to similar settings facing comparable health system and socioeconomic challenges. Future research involving multi-site studies and community-based surveillance is recommended to strengthen external validity and inform broader policy and programming efforts.

Data availability

The data supporting the findings of this study were obtained from patient records at Ruharo Mission Hospital and supplemented by qualitative interviews with caregivers and health workers. Due to ethical considerations and confidentiality agreements, the raw data are not publicly available. However, de-identified datasets and summary tables may be made available upon reasonable request to the corresponding author, subject to institutional approval and data protection protocols.

Conclusion

SB mortality in Western Uganda is not solely a medical issue but a reflection of broader socio-economic inequities. Addressing SB, therefore, requires multisectoral collaboration between health systems, social services, community leaders, and policymakers. Holistic interventions targeting poverty alleviation, caregiver empowerment, and stigma reduction could drastically improve survival outcomes.

Socioeconomic determinants play a critical role in shaping mortality outcomes for children with Spina Bifida. Children born in low-income households, with unemployed caregivers, and those dependent on unsafe water are at increased risk of death. The majority of deaths occur in the first five years of life, underscoring the need for timely interventions. Addressing financial, infrastructural, and social barriers will be essential in reducing mortality and improving the quality of life for children with SB in Uganda.

Limitations

Limitations included possible missing data in retrospective records, recall bias in caregiver interviews, and restricted socioeconomic variables.

Recommendations

- To mitigate the high mortality rate, financial protection mechanisms must be implemented. This includes establishing subsidy programs, health insurance waivers, or targeted cash transfers for caregivers, developing and strengthening family livelihood interventions to reduce poverty, alleviate the prohibitive costs of

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transport, medical supplies, and long-term care, thereby improving access to essential services.

- Geographic barriers to healthcare must be addressed through the decentralization of spina bifida services. This involves training staff and equipping lower-level health facilities, such as Health Centre IVs, to provide basic care, follow-ups, and referrals, thus reducing the distance families must travel for specialized treatment.
- Public health initiatives must integrate Water, Sanitation, and Hygiene (WASH) programs with disability care. Improving access to clean water sources and sanitation facilities at the household level is crucial for preventing the recurrent infections that are a leading cause of death among these vulnerable children.
- Community sensitization campaigns are essential to combat stigma and discrimination. Engaging cultural and religious leaders to challenge harmful beliefs and promote inclusion can reduce the social isolation of caregivers and encourage timely health-seeking behaviors for affected children.
- A strong focus on preventive strategies is paramount. This includes mandatory folic acid fortification of staple foods, alongside public education for women of reproductive age on the importance of prenatal supplementation, to reduce the incidence of neural tube defects like spina bifida.
- Investment in health system strengthening is critical. This entails training and deploying more neurosurgeons and rehabilitation specialists, while also ensuring a consistent and reliable supply chain for essential medical commodities like catheters, antibiotics, and surgical equipment.

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List of abbreviations

SB: Spina Bifida
NTDs: Neural Tube Defects
LMICs: Low- and Middle-Income Countries
WHO: World Health Organization
REC: Research and Ethics Committee

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Conflict of interest

The authors declare no conflict of interest.

Author contributions

Ndyowaawe Arron Bram conceptualized, designed, collected data, analysed, and wrote the manuscript. The drafts were reviewed and approved by Dr Matovu Daniel and Prof Kazobwe Francis.

Author biography

Ndyowaawe Arron Bram is a Master of Public Health (MPH) candidate at Bishop Stuart University. He specializes in disability interventions, childhood developmental disorders, health systems strengthening, and public health programming. He has practical experience in project management, particularly in designing, implementing, and evaluating disability-inclusive health and rehabilitation projects. His research interests include disability-inclusive programming, assistive technology, universal health coverage, and epidemiology, with a particular focus on how socio-economic determinants influence health outcomes among vulnerable populations in Low and middle-income countries.

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