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Editorial

Congenital Myelomeningocele and Hydrocephalus: A National Call for Urgent Intervention

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Abstract

Congenital myelomeningocele (MMC) and hydrocephalus (HCP) are common neurosurgical conditions in Libya. MMC involves the protrusionb of the meninges and spinal cord through open vertebral arches, leading to physical and cognitive impairments. In developing countries like Libya, healthcare disparities affect the treatment of these conditions. We are proposing a data collection protocol based on real-world cases previously documented in Libya.

Keywords: *Congenital Myelomeningocele, Hydrocephalus, Cognitive Impairments.*

Congenital myelomeningocele (MMC) and hydrocephalus (HCP) are prevalent neurosurgical conditions, especially in developing countries like Libya. MMC, a severe form of spina bifida, involves the protrusion of the spinal cord and meninges through an opening in the vertebral column, often leading to significant physical disabilities and neurological impairments. HCP, which commonly co-occurs with MMC, is characterized by the accumulation of cerebrospinal fluid in the brain, causing increased intracranial pressure. Both conditions pose substantial challenges for healthcare systems, especially in countries with limited resources, where access to advanced medical care and follow-up services may be inconsistent. In Libya, addressing MMC and HCP is particularly challenging due to disparities in healthcare infrastructure, inconsistent access to medical interventions, and limited data on patient outcomes. To improve care, there is a critical need for a comprehensive, standardized approach to data collection that captures all aspects of these complex conditions, from diagnosis to long-term outcomes. A national registry for congenital MMC and HCP, supported by an evidence-based data collection protocol, would facilitate better clinical decision-making, optimize treatment pathways, and reduce healthcare costs.

This paper proposes a structured protocol for the collection and management of data related to MMC and HCP in Libya. By implementing this protocol within a national registry, Libya's healthcare system can achieve significant improvements in both patient outcomes and cost-efficiency. The protocol emphasizes the need for real-time recommendations, consistent monitoring, and preventive interventions, particularly in maternal health, to address risk factors such as folic acid deficiency. Additionally, it highlights the role of data completeness, quality assurance, and feedback mechanisms in ensuring the long-term success of this initiative. Through this protocol, Libya has the opportunity to enhance the quality of care for patients with MMC and HCP while also addressing healthcare inequities across the country.

The establishment of a national registry for congenital myelomeningocele (MMC) and hydrocephalus (HCP) is crucial for improving healthcare outcomes in Libya. Previous published research in which a prospective study of 74 cases whose data were collected as per the pre-prepared data sheet in a single tertiary Institute in Tripoli (Tripoli Medical Center) from February 2017 and December 2017 showed of 74 patients, 20 (27%) patients were isolated MMC, 25 (34%) were isolated HCP, and 29 (39%) occurring in association with MMC. From a total of 74 patients, 34 (45%) were male and 40 (54%) were female. Furthermore, 27 (36%) patients delivered as premature infant and 47 (63%) were full term. The method of delivery was by cesarean section in 69 (93%) cases and by normal vaginal delivery in 5 cases (1%). The prenatal diagnosis of MMC and HCP using ultrasound was established in 70 (94%) cases.

Also, the study highlights other critical aspects such: Ventriculoperitoneal (VP) shunts inserted in 63 cases (85%). MMC repair was performed in 38 cases (51%). Most patients 55 (74%) were discharged routinely after VP shunt insertion and MMC repair. Further, folic acid intake by dose of (0.4 mg) orally was documented in 31 (41%) pregnant women, and 43 (58%) cases were not taken folic acid. As an indicator of the significant pressure on the health system, these cases also cause suffering for parents and incur high treatment costs [1].

The standardized data collection protocol proposed will significantly enhance the quality of care by ensuring that healthcare providers have access to comprehensive, accurate patient information. This enables precise, evidence-based diagnoses and treatment decisions, which are vital for managing complex congenital conditions like MMC and HCP. Access to national data will allow for the identification of treatment trends, improving clinical outcomes through the adoption of best practices tailored to the local context. By monitoring patient outcomes across the country, the registry will guide clinicians in making more informed decisions, reducing complications and improving long-term prognoses [2].

Moreover, the registry has significant cost-saving potential. Standardizing care based on national data helps optimize treatment pathways, which minimizes the need for repeat surgeries or other costly medical interventions. By identifying the most effective protocols for treating MMC and HCP, the registry will streamline care and eliminate inefficiencies, resulting in reduced healthcare costs. Furthermore, early and accurate data collection will help prevent unnecessary hospitalizations by identifying high-risk patients and implementing preventive interventions. This targeted approach to care will decrease the financial strain associated with emergency hospital admissions and prolonged hospital stays, which are often a consequence of unmanaged or recurrent complications in MMC and HCP patients.

In addition to optimizing treatment, the national registry will play a pivotal role in preventive health strategies, particularly concerning maternal folic acid intake [3]. Maternal folic acid deficiency is a known contributor to the development of neural tube defects (NTDs) like MMC. By capturing data on maternal health behaviors, especially the use of folic acid during pregnancy, the registry can guide public health campaigns to increase awareness and supplementation rates in high-risk populations.

This proactive approach will help reduce the incidence of MMC and HCP, leading to fewer cases that require complex and expensive medical interventions, thus further contributing to cost reductions in the healthcare system.

The long-term financial benefits of the registry are substantial. By eliminating redundant data collection processes and reducing administrative overhead, the registry will make healthcare data management more efficient. Centralized, electronic record-keeping reduces the need for manual entry, allowing clinicians to focus on patient care rather than paperwork. In addition, the registry will support academic research and informed policymaking by providing robust data on the prevalence, treatment outcomes, and geographic distribution of MMC and HCP. This data can help national authorities allocate healthcare resources more effectively, ensuring that specialized care is directed where it is needed most, further reducing costs associated with unequal or insufficient care.

In conclusion, the national registry for MMC and HCP will not only enhance patient outcomes but also lead to significant cost reductions across Libya's healthcare system. By streamlining data collection, guiding preventive measures, and improving treatment protocols, the registry will ensure more efficient use of resources while enhancing the quality of care. The long-term financial savings, through reduced hospitalizations, minimized complications, and efficient data management, will far outweigh the initial investment, making the registry a vital tool for both healthcare improvement and cost management.

Proposed Protocol for Data Collection: Enhancing Data Quality through Recommendations

1. Recommendations for Clinicians

To promote the collection of high-quality data, the system should offer evidence-based recommendations tailored to the patient's condition and the clinician's specialty:

- **Pre-Procedure Recommendations**: Prior to interventions like MMC repair or VP shunt insertion, the system should provide real-time recommendations based on clinical guidelines and historical patient outcomes, prompting additional data collection if necessary (e.g., prenatal diagnostics, consanguinity checks)
- **Post-Procedure Monitoring**: Clinicians should be guided to document post-surgical outcomes (e.g., paraplegia, foot deformities), ensuring all potential complications and recovery trajectories are comprehensively captured.

2. Proposed Database Protocol

A. Standardized Data Entry System: a unified system for data entry should be implemented across all departments involved in pediatric neurosurgery. This system should include:

- Mandatory Fields: All relevant patient information (e.g., demographics, diagnosis, treatment outcomes) must be captured using pre-defined, mandatory fields to ensure no critical information is omitted.
- Automated Validation: The system should have built-in mechanisms to check for inconsistencies or missing information, prompting users to complete or correct data before submission.

B. Patient Information Structure: Data should be organized in a structured, hierarchical format:

Demographic Data: Age, sex, consanguinity, maternal health factors (e.g., folic acid intake)

- Diagnostic Information: Type of condition (MMC, HCP, or both), anatomical site of MMC
- Intervention and Outcome Data: Surgical interventions (e.g., VP shunt, MMC repair) and patient outcomes (e.g., discharged, in-hospital mortality)

C. Temporal Data Tracking

To improve the comprehensiveness of longitudinal studies, data collection should incorporate:

- Time-Stamped Entries: Each data entry should be time-stamped, including details of the patient's developmental milestones and treatment dates, enabling better tracking of the progression of conditions like MMC and HCP
- Automated Follow-Up Reminders: Automated prompts should notify healthcare providers when follow-up data on patients is due, improving the completion rate of longitudinal data collection.

3. Recommendations for Data Completeness

A feedback mechanism should be implemented where the system continuously evaluates the completeness of the collected data and suggests:

- Missing Information Alerts: If any mandatory fields (e.g., head circumference, surgical intervention details) are left incomplete, the system should alert the clinician to enter the required data
- Best Practice Protocols: For common issues like prenatal folic acid intake, the system should recommend adherence to national guidelines (e.g., folic acid supplementation) and suggest relevant data points to document these interventions

4. Data Validation and Quality Assurance

To ensure the collected data maintains high integrity:

- Internal Audits: Periodic audits should be conducted to verify the accuracy and completeness of the data. Any discrepancies should be flagged, and recommendations for corrections should be communicated to the data collection teams.
- Peer Review Mechanism: Clinicians should have access to peer reviews of their data collection processes. This would foster a collaborative environment where high data quality standards are maintained through shared accountability.

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