EXECUTIVE SUMMARY

Although the incidence of spina bifida and hydrocephalus (SB/HCP) is decreasing in some regions of the world, low- and middle- income countries (LMICs) are still grappling with a large population of such cases. In recent years, much has been learned about developing a coordinated effort to properly manage and care for children with these complex conditions. Success from these efforts, including in many LMICs, could and should be shared with other countries in hopes of improving many lives. Guidelines and recommendations have been propagated previously with limited success, duplicating some approaches while others remain complex or resource consuming. A rejuvenated and focused effort to collect the best evidence from different backgrounds is offered to support countries with a significant SB/HCP burden.

In this publication we share policy recommendations crafted to guide comprehensive management of SB/HCP. Outcomes for these children are often affected by poverty, poor infrastructure, and the scarcity of trained personnel and facilities. In addition, long-term outcomes are diminished when healthcare inequality is experienced by individuals with such disabilities, often adversely affecting access to medical services. To address this global burden and disparities we identified policy options, especially targeting LMICs.

Multiple concepts (as advised by WHO) are suggested, along with new initiatives or programmatic changes to existing policies. These recommendations are designed to provide healthcare workers, hospitals, ministries of health, governments, and other policymakers to develop a framework for strengthening their approach to SB/HCP. We recognize that prevention measures, early detection and intervention, with proper and holistic care of these individuals will significantly improve their lives.

The recommendations are organized into sections on Screening and Surveillance, Prevention, Prehospital care, Surgical systems, Rehabilitation, and Transitional/follow-up care. They are discussed in terms of health system building blocks such as a) Infrastructure, b) Workforce, c) Service Delivery, d) Financing, e) Information Management, and f) Governance.

INFRASTRUCTURE

Prevention and surveillance/screening efforts might include routine head circumference/percentile measurements, and offer universal folic acid fortification. In addition, improved access to obstetric facilities supported by an educated healthcare workforce will significantly improve outcomes.

To assure safe and prompt prehospital care, it may be beneficial for LMICs to prioritize effective referral networks, safe roads, and comprehensive ambulance systems that follow the WHO Emergency Care System Framework. It is recommended referral level hospitals be prepared to provide vaginal or cesarean section deliveries and certain urgent surgical services.

The catchment area of a SB/HCP center should be determined, and it is beneficial that 80% of the population live within two hours of a triage center.

Referral systems from first-level hospitals are essential, and increased transportation options for disabled patients will increase access to these facilities. More rehabilitation centers are needed, and it may be beneficial to reserve space and resources for in-hospital services (also affords accessibility). It is recommended that pediatric district level hospitals be equipped with neonatal sepsis management capabilities. Microbial diagnostics and use of Common Data Elements also help improve patient care.

WORKFORCE

The shortage of pediatric subspecialists is recognized, and for LMICs some goals are insurmountable in the near future. Task shifting and responsibility sharing with other specialties is a viable option to increase the workforce, especially for SB closure or urgent HCP management. Increased use of allied health professionals will likely extend the availability and scope of SB/HCP care into rural areas.

Continued medical education at multiple levels might maintain, or even increase a motivated workforce offering a long-term benefit. Training centers are needed to address the workforce deficit, to provide high-quality healthcare and offer educational opportunities across all platforms of care delivery. Targeted prospects for caregivers, medical personnel, and community healthcare workers are necessary, emphasizing training in early recognition, navigating the referral network, and identifying other opportunities.

SERVICE DELIVERY

All children who are referred to tertiary hospitals benefit by receiving prompt attention and treatment, preferably in dedicated and well-equipped pediatric intensive care units or high dependency units. Public health education and community-based screening will likely improve access to healthcare, and decrease stigmatization that often inhibits seeking medical help.

Telemedicine technology can be scaled up to optimize access to care or referral systems, and locally compiled prospective databases will help guide their proper use.
Services can be tailored to specific age groups or level of disability, with emphasis on transitioning patients from childhood to adulthood. Gradually integrating patients into society with improved abilities might decrease the long-term burden (individually and socio-economically).

Prevention efforts and public education campaigns are very beneficial, and every woman of child-bearing age should have access to affordable folic acid supplementation. In addition, it is recommended that all centrally processed grain should be fortified with folic acid immediately.

FINANCING

Inadequate finances often pose a barrier for SB/HCP patients and their families, and some options may be considered to improve this concern. Governments can reduce the financial burden by embedding SB/HCP care into a universal health coverage package, providing affordable transportation or offering easier access to medical care (i.e. telemedicine visits). They can encourage a public/private partnership, or perhaps utilize a shared input and strategic model for cost allocation of goods and services. Healthcare coverage might extend to transitional/follow-up care, and include preventive measures such as folic acid fortification and supplementation.

Active support of non-governmental organizations (NGOs) can fill in strategic gaps in some instances, and international partnerships may assist in funding training and capacity building for SB/HCP care. Government funding for health research with improved screening measures and a facilitated referral process, can reduce the potential future financial burden (individually and socio-economically). This can sometimes be achieved in conjunction with local care providers and international partnerships.

INFORMATION MANAGEMENT

Surgical centers capable of managing SB/HCP can collect data on a regular basis, using national level registries or using web-based platforms to host data. Tracking of regional incidence information, trending, and use quality of life metrics during follow-up SB/HCP visits will aid in this effort. Data collection, from SB/HCP identification to time of presentation (including routine vs. emergency), will aid future referral options.

Tracking pediatric specialist workforce with perioperative morbidity and mortality, as well as accurate collection of rehabilitation outcomes data will guide resource allocation.

GOVERNANCE

The responsibility of surgical system governance for SB/HCP management typically lies within local control. LMICs can focus on long-term internal sustainability by improving legislation and education to protect rights of SB/HCP patients, possibly using regional multidisciplinary teams to oversee the process.

Prioritization of infant mortality as a National Hospital Metric, using government-sponsored medical care for infants, mandatory screening/reporting of preventable childhood illnesses and licensing of skilled birth attendants can facilitate these data collections. Supporting the Ministry of Health in developing a national referral network and encouraging policies favorable to promote NGO support, might expedite these concerns.

CONCLUSION

The commitment to invest in the comprehensive management of SB/HCP, including prevention and prehospital care, will doubtlessly save many lives and prevent a greater number of disabilities worldwide. We encourage all governments to adopt the Comprehensive Spina Bifida and Hydrocephalus Policy Recommendations, as a tangible way to begin “reducing by one third premature mortality from non-communicable diseases through prevention and treatment” (per WHO SDG 3.4.1).

References

1. WHO | SDG 3: Ensure healthy lives and promote wellbeing for all at all ages [Internet]. WHO. [cited 2020 Jan 3];Available from: http://www.who.int/sdg/targets/en/