

Comprehensive Policy Recommendations
for the Management of Spina Bifida & Hydrocephalus
in Low- & Middle-Income Countries



NOVEMBER 2021

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FOREWORD

In November 2020, the Member States of the World Health Organization (WHO) adopted the World Health Assembly resolution 73.10 asking the Director-General to develop an Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders. Notably, the action plan aims to use “an integrated, person-centered framework for the prevention, diagnosis, treatment, and care of people with neurological disorders” and asks the Member States to develop “policies, plans, and legislation relating to neurological disorders, whether as separate instruments or integrated into other planned multisectoral actions”. Accordingly, these recommendations for the comprehensive management of spina bifida and hydrocephalus for low-and middle-income countries (LMICs) represent the collective effort of a group of advocates, and experts from around the world to compile the best evidence to date. They utilize the WHO health systems and person-centered framework used by many ministries of health to facilitate their integration.

We intentionally chose two pediatric neurosurgical conditions, spina bifida and hydrocephalus, to highlight the massive pediatric surgical needs in LMICs as well as the paucity of prevention efforts despite overwhelming supporting scientific evidence. While the strengthening of capacity to detect and holistically treat spina bifida and hydrocephalus are crucial, strategies to prevent these conditions are indispensable to the overall disease management and cost effective. Contributions from members of the International Society for Pediatric Neurosurgery and the Global Alliance for the Prevention of Spina Bifida proved to be especially valuable.

Healthcare workers, researchers, and public health practitioners came together for this project in providing strategic guidance and technical support to policymakers. Accordingly, the research team, with guidance from the advisory group of experts, initially reviewed the available literature to develop a comprehensive set of recommendations for the management of spina bifida and hydrocephalus in LMICs. The advisory group, especially its members living and working in LMICs, helped with contextualizing the recommendations.

The goal of this document is not limited to just raising awareness of the unmet pediatric neurosurgical needs and the importance of prevention. We envision the inclusion of the recommendations in the WHO’s Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders. Additionally, it is our hope that LMICs adopt the recommendations into their national surgical system strengthening efforts pursuant to the World Health Assembly resolution 68.15, “Strengthening of

Emergency and Essential Surgical Care and Anesthesia as a Component of Universal Health Coverage”. Furthermore, the team of contributors to this document stand ready to support the country-led implementation of these policies to reduce death and disabilities from spina bifida and hydrocephalus among children living in LMICs.

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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).

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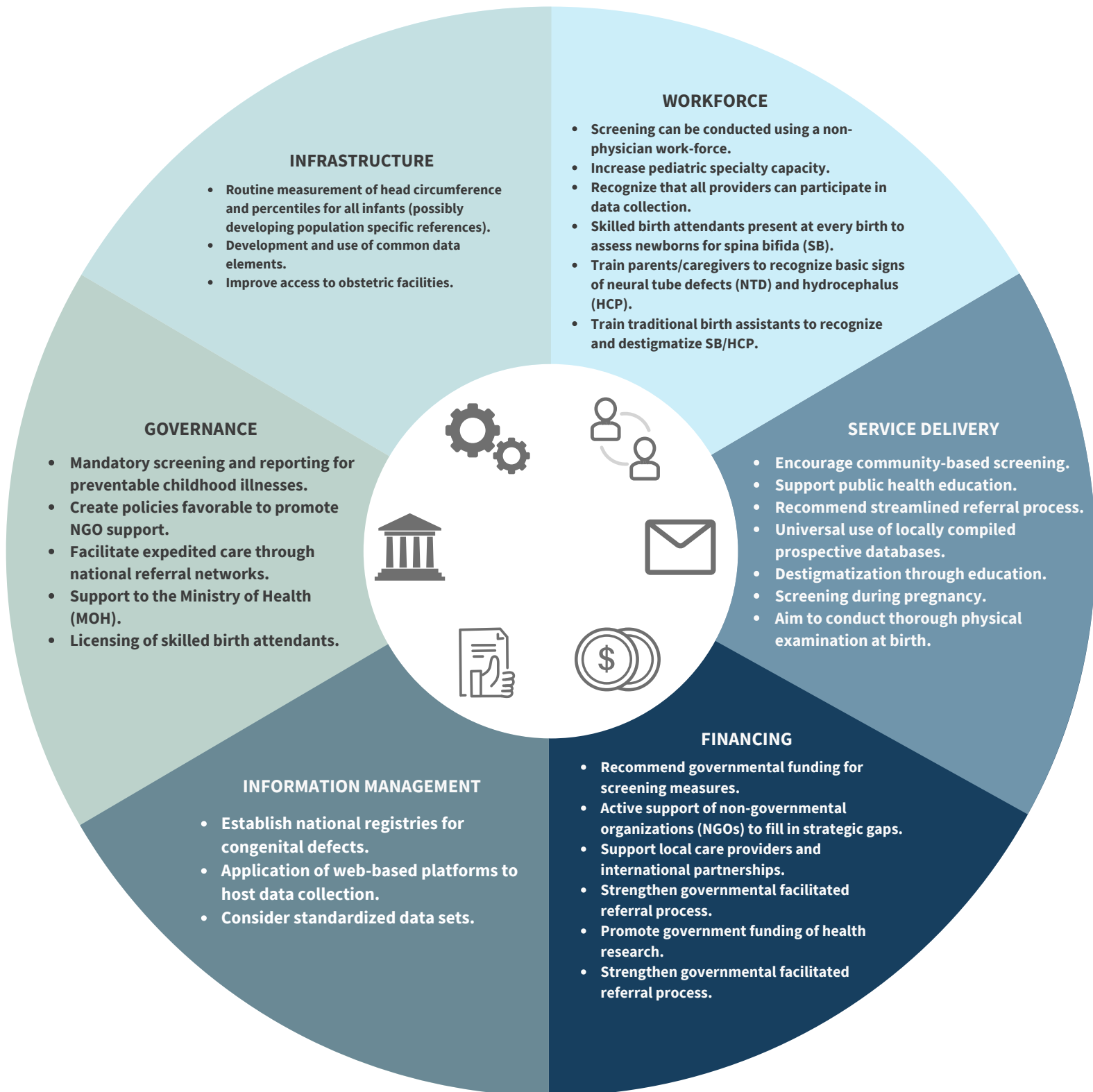
1. WHO | SDG 3: Ensure healthy lives and promote wellbeing for all at all ages [Internet]. WHO. [cited 2020 Jan 3]; Available from: <http://www.who.int/sdg/targets/en/>

ACRONYMS & ABBREVIATIONS

CDC	CENTERS FOR DISEASE CONTROL
CHSB	CURE HYDROCEPHALUS AND SPINA BIFIDA
ETV	ENDOSCOPIC THIRD VENTRICULOSTOMY
HCP	HYDROCEPHALUS
HIC	HIGH-INCOME COUNTRY
ISPN	THE INTERNATIONAL SOCIETY FOR PEDIATRIC NEUROSURGERY
LMIC	LOW-AND MIDDLE-INCOME COUNTRY
MOH	MINISTRY OF HEALTH
NGO	NON-GOVERNMENTAL ORGANIZATION
NTD	NEURAL TUBE DEFECT
PCR	POLYMERASE CHAIN REACTION
QUALAS	QUALITY OF LIFE ASSESSMENT IN SPINA BIFIDA
SAO	SURGICAL, ANESTHETIC AND OBSTETRIC
SBA	SPINA BIFIDA ASSOCIATION
SB	SPINA BIFIDA
SDG	SUSTAINABLE DEVELOPMENT GOAL
SHIP	SPINA BIFIDA AND HYDROCEPHALUS INTERDISCIPLINARY PROGRAMME
TRAQ	TRANSITION READINESS ASSESSMENT QUESTIONNAIRE
UNICEF	UNITED NATIONS CHILDREN'S FUND
US	UNITED STATES
USD	UNITED STATES DOLLARS
WFSA	WORLD FEDERATION OF SOCIETIES OF ANESTHESIOLOGISTS
WHO	WORLD HEALTH ORGANIZATION

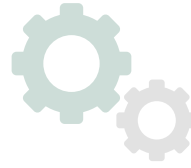
SECTION 1:

SCREENING AND SURVEILLANCE



WE CAN'T MANAGE WHAT WE DON'T MEASURE - COUNTING EVERY CASE OF SPINA BIFIDA AND HYDROCEPHALUS IS THE FIRST STEP TO NATIONAL MANAGEMENT.

INFRASTRUCTURE



- **Routine measurement of head circumference and percentiles for all infants.**

The World Health Organization (WHO) currently recommends that height and weight be routinely measured throughout infancy and childhood in order to screen for acute malnutrition (1). Similarly, we recommend that the routine measurement of head circumference be considered a standard of care at every encounter with a healthcare provider, in order to screen for undiagnosed neurological illnesses (2).

The materials required for such measurement are minimal, measuring tape and WHO/Centers for Disease Controls (CDC) head circumference charts (3). In accordance with the CDC, we recommend use of the WHO Growth Standard Charts from birth until two years of age, and CDC Growth Reference Charts for children two to 19 years (4). No specific facilities are required as such measurements can be performed in any location, including the child's home or village. In addition, these data can be used to develop population specific head circumference ranges to aid the local medical providers (5).

- **Development and use of common data elements.**

Efficient surveillance for HCP requires common data elements that allow for the combining of separate databases for aggregate research. We recommend the use of online data registries by care providers in pediatrics and obstetrics departments, health centers, and district hospitals. At minimum, such databases may include basic demographics, head circumference, radiographic findings, therapeutic data, and contact information for follow-up.

The materials required for such data collection include access to the internet on a personal electronic device. No specific facilities are necessarily required.

- **Improve access to obstetric facilities.**

Recognition of SB/HCP ideally occurs prior to birth, facilitating timely referral for specialized care. We recommend that all mothers have access to diagnostics, quality obstetric care, and delivery facilities (6). In some cases, special attention or support may be needed to establish diagnostic centers.

WORKFORCE



- **Screening can be conducted using a non-physician workforce.**

Measurement of head circumference is technically simple and easily reproducible among providers of various health and educational backgrounds, and can also be performed by parents (7,8). If a primarily non-physician workforce is to be used, it is important to train them to systematically measure head circumference during all routine encounters. We recommend that all providers undergo a brief, standardized online training module to improve the quality and accuracy of measurement, which is provided by the CDC and free of cost (9).

- **Increase pediatric neurosurgical capacity.**

Increased screening for HCP will inevitably increase the rate of diagnosis and referral to neurosurgical specialists. It will therefore be necessary to simultaneously increase the number of providers trained to triage and surgically treat HCP, using both shunting and endoscopic techniques.

- **Recognize that all providers can participate in data collection.**

Data collection can be performed by any provider with minimal additional training. This includes nurses, medical students, medical officers, physicians, and research assistants. That being said, we recommend that any clinical parameters such as radiographic findings and surgical information be first interpreted and compiled by a physician.

- **Skilled birth attendants present at every birth to assess newborns for SB/HCP.**

The most important component in the screening for NTDs is an adequately trained workforce of birth attendants. We corroborate the WHO recommendations for “skilled care at every birth” (10). In particular, the recommendations specify that the trained workforce should be capable of “assessing the newborn at birth and giving immediate care”, in addition to other core skills (11). In the case of SB this will include inspection, recognition of the NTD, and proper placement of dressings to protect any exposed neural elements. This workforce will likely differ based on regional variation, but will largely be composed of obstetricians, primary care physicians, midwives, and nurses with midwife skills (12).

- **Train parents/caregivers to recognize basic signs of NTDs and HCP.**

In addition to healthcare workers, well informed parents play an important role in SB awareness and screening. Every effort should therefore be made to make educational materials freely available to the general population regarding the basics of disease recognition in newborn infants (13).

- **Train traditional birth assistants to recognize and destigmatize SB/HCP.**

In many parts of the world, the majority of births are attended by traditional birth attendants without any formal medical training (14). It has been shown that training these traditional providers on the basics of birth complication management could lead to reduction in maternal and perinatal mortality rates (15). Countries in which much of the current workforce comprises these traditional providers can make every effort to educate these providers, and incorporate them in the referral process for infant diseases.

SERVICE DELIVERY



- **Encourage community-based screening.**

We recommend that head circumference and percentile measurement be a standard component of all health encounters throughout childhood. However, in many resource-limited settings, access to routine healthcare is unavailable, unreachable or unaffordable. In such scenarios, great success has been shown with the use of community-based screening methods, in which community members or public health field workers are trained to lead local screening efforts, and ensure that no children are missed (15). While previous efforts were centered around the diagnosis and treatment of severe acute malnutrition, we propose that head circumference be made an additional component in these screening programs, and ideally it should be measured at least once before the age of six months (3).

- **Support public health education.**

In order to improve knowledge on the need for HCP screening, and on when to seek medical attention, simple instructional flyers, posters, videos, and social media posts can be utilized to educate the general populace and local healthcare workers (16,17).

- **Recommend streamlined referral process.**

Screening is only useful if it then leads to efficient referral and subsequent care. Based upon this it will be important for a streamlined referral process to be in place for all positive screenings. We recommend that local neurosurgical centers of excellence be identified and listed. Such lists can be distributed to all public health workers so that referral and directions can be given immediately upon positive screening to minimize the risk of loss to follow-up (18,19).

- **Universal use of locally compiled prospective databases.**

We recommend that every newly diagnosed case of SB/HCP, and every patient that undergoes operative intervention, be included in a locally compiled and owned prospective database to improve both the quantity and quality of available epidemiological data.

- **Destigmatization through education.**

In many regions of the world there exists significant social stigma surrounding congenital defects and children with disabilities, creating detrimental delays in care (9,18). Many of these stigmas are related to deep-seated cultural beliefs, and might be addressed in a culturally sensitive fashion. It is important to educate parents, and the community regarding the basics of disease recognition and care in an appropriate cultural context (20). Such education can be accomplished with community engagement, posters, social media campaigns, online video tutorials, and local media and advertisement campaigns.

- **Screening during pregnancy.**

Close monitoring during pregnancy can identify issues needing attention, or perhaps coordinate delivery and postnatal care. Ready accessibility of ultrasound and imaging facilities can improve maternal and fetal management. In some cases, early and planned interventions can be offered at advanced centers.

- **Aim to conduct thorough physical examination at birth.**

Every infant should receive a thorough physical examination immediately following delivery in order to identify signs of acute distress and congenital malformation. Whether delivery occurs at home or in a medical facility, it is suggested that every child have access to a care provider who can recognize NTDs in addition to other neonatal diseases, and subsequently refer to higher levels of care when appropriate (11).

FINANCING



- **Recommend governmental funding for screening measures.**

Screening for HCP is relatively cheap, straightforward, and cost effective (20,21). Given that childhood HCP is a treatable condition (with potentially devastating results if left unmanaged), we recommend that local governments ensure that their populace is adequately screened. We therefore recommend the allocation of governmental healthcare funding for HCP screening as a way to achieve sustainable development goal (SDG) 3.2, and to improve the national infant and child mortality rate.



SDG 3.2: End all preventable deaths under 5 years of age

- **Active support of NGOs to fill in strategic gaps.**

Screening efforts can also be coordinated and led by NGOs, as long as such endeavors are done in coordination with the local health and surgical referral system (22).

- **Support local care providers and international partnerships.**

We recommend that data collection be primarily led by the treating surgeons and health providers throughout the clinical care of these patients. Additionally, research and technical support can be provided by local academic institutions and international clinical partnerships (23,24). As such, direct costs to the local hospitals and governmental health structures can be minimal beyond compensation for part-time data collection specialists, and access to internet-based data platforms (25).

- **Promote government funding of health research.**

As the local medical system grows, a plan may be set in place for the allocation of funds to support and incentivize high quality medical research. Such funding will promote continued growth of research infrastructure at the local level.

- **Strengthen governmental facilitated referral process.**

Following recognition, the referral process is imperative to efficient disease treatment. Beyond delays in deciding to seek care, it is known that additional delays can occur in reaching and receiving care once arrived at a treating facility. We recommend that the governmental health system facilitate safe, timely, and affordable access to neurosurgical care with subsidies as needed for the most economically vulnerable populations (23).

INFORMATION MANAGEMENT



- **Establish national registries for congenital defects.**

We recommend the close monitoring of geographic and demographic data throughout the screening process, so that geospatial data may be used to identify areas of greater incidence and prevalence. Tracking of regional incidence data, and tabulating such information will allow for more efficient use of preventative and therapeutic resources.

- **Application of web-based platforms to host data collection.**

The use of web-based data collection platforms allows for remote analysis of data, and collaboration between institutions of the same country and multinational institutions.

- **Consider standardized data sets.**

We recommend the use of a set of core common data elements which outlines the minimum variables to be collected for each patient included in the database. Such uniformity of data collection will allow for aggregation of data between different databases and data storage platforms.

GOVERNANCE



- **Mandatory screening and reporting for preventable childhood illnesses.**

Local governments can adopt policies of mandatory screening for standard preventable pediatric illnesses, including HCP. Parents may be incentivized to bring their children for routine preventative screening visits using educational campaigns.

Follow through on the World Health Assembly Resolution 63.17 recommendation to “strengthen registration and surveillance systems” (26).

- **Create policies favorable to promote NGO support.**

NGOs often provide a strong foundation of medical care in many resource-limited settings. Local governments might create incentives for NGOs and charitable organizations to operate in their countries without difficulty, and even provide tax incentives for such organizations to set up operations within their borders.



- **Facilitate expedited care through national referral networks.**

Multiple components have to be in place and well-coordinated for patients to actually receive care after positive screening. These range from viable and affordable transportation infrastructure, availability of surgical specialists at centers of excellence, and adequate financial support to cover medical costs. The local government will be primarily responsible for designing the referral network that will accompany the screening process.

- **Support to the MOH.**

The MOH must be the epicenter of all local epidemiologic data collection. Adequate technical support, funding, and we recommend resources, must be allocated to the MOH to allow for growth in research infrastructure and data collection. When feasible, link the data to global platforms such as the WHO Global Health Observatory.

- **Licensing of skilled birth attendants.**

Governments can institute mandatory licensing processes for skilled birth attendants with continuing medical education, and maintenance of certification requirements in order to ensure a minimum level of competency throughout their careers. It serves as an incentive for them to complete education requirements regarding maternal care and screening for childhood illnesses, which eventually helps improve patient safety (11).

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SECTION 2:

PREVENTION

INFRASTRUCTURE

- Improve access to district level hospitals with pediatric capabilities for treatment of neonatal sepsis.
- Recommend that tertiary care hospitals have neonatal capabilities for severe cases of neonatal sepsis.
- Suggest the use of microbial diagnostics.
- Encourage folic acid fortification.
- Support improved education of the healthcare workforce.

WORKFORCE

- Improve access to obstetrics and gynecology care.
- Suggest sufficiently staffed first-level and national-level hospitals with pediatricians, neonatal intensivists, and infectious disease specialists.
- Encourage involvement by family support and advocacy groups, obstetric associations, and NGOs.
- Fortification using existing milling infrastructure and workforce.
- Supplementation facilitated by pharmacists, nutrition experts, primary care providers, and NGOs.
- Education of the current health workforce and future parents is helpful.

GOVERNANCE

- Propose government sponsored medical care for infants.
- Prioritization of infant mortality as a national hospital metric.
- Incentivized folic acid supplementation.
- Recommend mandatory folic acid fortification.
- Government supported education is crucial to a National Prevention Campaign.

SERVICE DELIVERY

- Education of parents regarding signs and symptoms of neonatal sepsis.
- Access to early antibiotic therapy.
- Suggest that all centrally processed grain be fortified with folic acid immediately.
- Strive to have every female of child-bearing age to have access to affordable folic acid supplementation.
- Stimulate public education campaigns.

INFORMATION MANAGEMENT

- Creation of national level registries.
- Use of secure web-based platforms to host data collection.
- Recommend common data elements.

FINANCING

- Strengthen government funded care for infants.
- Folic acid fortification or supplementation.
- Funding to support education.



EVIDENCE SHOWS FOLIC ACID SUPPLEMENTATION PREVENTS SPINA BIFIDA AND TREATMENT OF NEONATAL SEPSIS PREVENTS HYDROCEPHALUS.

FOLIC ACID

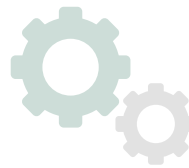
- Current evidence suggests that 0.4 mg (400 ug) per day of folic acid cuts down the risk of SB and other NTDs. In order to reduce the incidence of SB, it is recommended that women of childbearing age consume 0.4 mg of folic acid per day for the purpose of preventing spina bifida or other NTDs.
- Globally, 88 countries have legislation mandating fortification of wheat flour or rice.
- Governments may add folic acid to the flour to help in the prevention of SB on the national scale.

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INFRASTRUCTURE



- Improve access to district level hospitals with pediatric capabilities for treatment of neonatal sepsis.

Given that access to care in low-and-middle income countries (LMICs) mainly occurs at district hospitals, it is imperative that these facilities are equipped and staffed to adequately care for NTDs and neonatal sepsis (1). A comprehensive network of district level hospitals that provide access for the local population may be put in place. It is desirable that district level hospitals have wards dedicated to the care and management of pediatric, and ideally neonatal conditions. The basic equipment at these wards often include incubators, ventilators with appropriate settings for neonates, and standard bedside monitoring equipment compatible with pediatric care. Additionally, broad spectrum antibiotics need to be available to empirically treat neonatal infections until a specific source pathogen can be identified (2).

- Recommend that tertiary care hospitals have neonatal capabilities for severe cases of neonatal sepsis.

It is recommended that a national level referral center have a specialized/dedicated care area, or a neonatal intensive care unit, prepared to care for the sickest patients that district hospitals may lack the capacity to adequately manage. Imaging capabilities would need to include cranial ultrasound, computed tomography, and magnetic resonance imaging (3).

- **Suggest the use of microbiology diagnostics.**

We recommend the availability of diagnostic testing via microbial culture at every district hospital, either at the local hospital laboratory or via send-out to the national referral center. In addition, national centers may be equipped with polymerase chain reaction (PCR) diagnostic equipment in order to identify bacterial specimens which do not grow in culture (4).

- **Encourage folic acid supplementation.**

Folic acid insufficiency should be understood in the broader concept of micronutrient deficiency which impacts more than three billion people worldwide. Fortification of staple food or salt is superior to supplementation strategies for multiple reasons. Fortifying foods or salt will allow women to have normal levels of folate without an attendant change in dietary behaviors. Importantly, ideal serum levels of folic acid are reached within three months of fortification, thus full prevention benefits are achieved within a very short time after fortification is implemented (5,6).

Supplementation does not seem to be as effective in places where public education is limited because folic acid needs to be given for at least one month before pregnancy (7). By contrast, a meta-analysis by Blencowe et al., found that fortifying wheat flour could reduce NTDs worldwide by 46% (8). The risk of a live birth with SB with optimal serum or red blood cell levels of folic acid is 6/10000 births. Administration of folate > 1mg/day decreases SB incidence and does not cause significant harm (9). Furthermore, the risk of increased cellular proliferation or neoplasia is non-existent at fortification level doses of folic acid. Recent progress with salt fortification appears to be a promising modality to circumvent logistic issues related to wheat and grain fortification. Cost effectiveness studies on folic acid fortification have demonstrated approximately 150 United States Dollars (USD) of return in cost savings for every dollar invested in folic acid fortification.

We suggest folic acid supplementation be provided to women of child-bearing age. The supply of folic acid may be supported by funding from NGOs and by governmental funding, as available. It is recommended that folic acid be supplied to all women of child-bearing age who meet with healthcare workers at affordable or no cost to the women. This encourages the distribution of a safe and affordable supply of oral folic acid supplements (10,11,12).

The International Society for Pediatric Neurosurgery (ISPN) Spina Bifida Global Taskforce, offered a resolution to reduce the folic acid-preventable spina bifida and anencephaly through mandatory fortification of staple foods by 2030 (13).

The Taskforce recommended that all governments require mandatory fortification in hopes of providing women of reproductive age with 150 µg/day of folic acid (minimum as recommended by WHO).

- **Support improved education of the healthcare workforce.**

We encourage more prevalent education of the healthcare workforce to understand the importance of folate in preventing NTD through online modules and printed materials.

Healthcare workers are tasked with educating women, especially adolescents and women of child-bearing age, about the risks of NTD and how this can be impacted by supplementation of folic acid. This is especially important for women who have already had a previous pregnancy impacted by a NTD (10,11,12).

WORKFORCE



- **Improve access to obstetrics and gynecology care.**

In many cases, the etiology of neonatal sepsis is related to pathogens carried by the mother and transferred at the time of birth (4,14). As such, access to standard prenatal care, vaccines, and pre-partum treatment of known causative pathogens are important methods of preventing neonatal sepsis and ultimately post-infectious HCP (15,16).

- **Suggest sufficiently staffed first-level and national-level hospitals with pediatricians, neonatal intensivists, and infectious disease specialists.**

It is suggested that district level hospitals be staffed with general practitioners with the ability to recognize and stabilize septic infants, while national level hospitals may have trained physicians with specific expertise in neonatal critical care and infectious diseases (16). In addition, nurses and ancillary staff with training in neonatal management, as well as laboratory technicians skilled in microbial culture and PCR analysis, are essential personnel (16).

- **Encourage involvement by family support and advocacy groups, obstetric associations, and NGOs.**

Prevention takes a team effort, involving healthcare providers working closely with families and caregivers. The most effective approach would be to engage the community and social groups to be involved actively wherever possible. Several options include social media and digital communication, in conjunction with government recognized programmes. This may help diminish the hesitancy towards preventive measures, and gather support from the non-traditional medical providers.

- **Fortification using existing milling infrastructure and workforce.**

Only 1/3 of the world's flour from industrial mills is fortified, contributing to the modest 18% effectiveness of prevention of folic acid preventable SB and anencephaly that could be prevented. Many mills have existing infrastructure, but they fortify selectively to reflect market preferences. One study suggests that 71 countries have the immediate potential to fortify wheat flour and prevent 57000 NTDs (3). Fortification can be achieved immediately in countries with existing milling infrastructure (13).

We recommend the use of the current milling infrastructure and workforce to include folate in commonly used wheat flour, maize flour, and rice. We encourage government support for existing milling infrastructures which are equipped to fortify. For those lacking the infrastructure for fortification, government investments would yield high returns and reflect high levels of cost effectiveness (13).

- **Supplementation facilitated by pharmacists, nutrition experts, primary care providers, and NGOs.**

In the absence of a robust fortification program, pharmacists and healthcare workers may be tasked to prescribe and dispense folic acid supplements. NGO support to continue funding for supplementation may be a good alternative in some situations.

- **Education of the current health workforce and future parents is helpful.**

Healthcare workers can be encouraged to provide education to schools, hospitals, and outreach clinics. Education should be readily provided and available regarding the causes of SB/HCP, the means of prevention, and the morbidity of those impacted by it. Programs to decrease the incidence of SB/HCP can be provided in schools or civic organizations to increase awareness, and it is suggested that non-traditional medical providers be included in this effort.

SERVICE DELIVERY



- **Education of parents regarding signs and symptoms of neonatal sepsis.**

In Uganda, over 75% of patients with post-infectious HCP had a febrile illness in the first month of life (17). Educational campaigns may be targeted at parents with young infants to inform them of the importance of promptly presenting to a medical provider in the event of febrile illness.

- **Access to early antibiotic therapy.**

Preferably, every infant will have immediate access to general medical care for early diagnosis of infection and initiation of antibiotic therapy (18). Care can then be escalated to district and referral level hospitals as needed in the event of sepsis and life-threatening critical illness.

- **Suggest that all centrally processed grain be fortified with folic acid immediately.**

Given that only 1/3 of the world's flour from industrial mills is currently fortified, this can be an important first target for every government without the need for significant expansion of workforce or infrastructure. This would increase the rate of NTD prevention from 18 to 34 (19). Additional efforts may then be made to increase fortification in non-grain based diets and regions with non-industrial milling.

- **Strive to have every female of child-bearing age to have access to affordable folic acid supplementation.**

Oral folic acid supplementation is a low-cost intervention with minimal risk. We recommend that every woman of child-bearing age have local access to affordable folic acid supplementation which can be taken throughout pregnancy.

- **Stimulate public education campaigns.**

While the availability of micronutrients such as folic acid is important, it will be even more important to provide adequate education to the general population to increase its usage and promote awareness of NTD prevention (19,20). Such efforts can be accomplished at low cost with social media campaigns, informational videos, and health provider education (20).

FINANCING



- **Strengthen government funded care for infants.**

Given the huge economic burden of neonatal sepsis in sub-Saharan Africa, local governments can help prioritize the treatment of this dreadful complication (21). It is in the government's best financial interest to provide medical care for these infants, regardless of the family's ability to pay, in order to prevent further sequelae, such as progressive HCP and long-term disability. The provision of such care will help in keeping with SDG 3.2, with the aim of reducing infant and child mortality rates (22).

- **Folic acid fortification or supplementation.**

The direct cost of treating individuals with NTDs is orders of magnitude greater than the cost of prevention via diet or salt fortification with folic acid. Benefit-cost ratios for folic acid fortification range from 22 to 110 in the United States, 30 in South Africa, and 5 to 35 in Australia. These extraordinary ratios suggest profound returns on investment. The cost of caring for a person with a NTD would include surgery, hospitalizations, and rehabilitation.

This suggests a 30-fold return of expended funds for improving SB care (23). Based upon this, we recommend that governments allocate resources to prioritize fortification of food supply with folic acid. Using existing milling infrastructure would temper the cost of creating new milling systems for the implementation (24).

We recommend governments provide funding for folic acid supplementation at affordable cost to all women of child-bearing age. In addition, policies that incentivize external NGOs to supply folic acid to the local populace may be adopted. As folic acid is essential for reducing morbidity and mortality in children from LMICs, governments may also provide funding or subsidies in areas where NGO support may not be available.

- **Funding to support education.**

Funding to support public education about SB and its causes is essential for the prevention of NTDs. We encourage governmental partnership with NGOs, such as International Federation for Spina Bifida and Hydrocephalus and Child Help International, as available.

INFORMATION MANAGEMENT



- **Creation of national level registries.**

We recommend the creation of national level registries that will track the incidence, geographic location, and causes of neonatal sepsis. Such registry level data would allow for better prospective analysis and understanding of patients who go on to develop HCP, and will assist in determining how such cases might be better prevented (1).

We recommend the close monitoring of geographic and demographic data, so that geospatial data may be used to identify areas of greater incidence and prevalence. Such information will allow for more efficient use of preventative and therapeutic resources in areas of highest impact.

- **Use of secure web-based platforms to host data collection.**

The use of secure web-based data collection platforms allows for remote analysis of data and collaboration between institutions in the same country and multinational institutions.

- **Recommend common data elements.**

We recommend the use of a set of core common data elements which outlines the minimum variables to be collected for each patient included in the database. Such uniformity of data collection will allow for aggregation of data between different databases and data storage platforms.



- **Propose government sponsored medical care for infants.**

We propose governmental policy that supports sponsored medical care for infants and children less than five years of age. Such policy is expected to eliminate financial barriers which may prevent the most economically vulnerable populations from accessing care.

- **Prioritization of infant mortality as a national hospital metric.**

As the MOH conducts local hospital evaluations, we propose the use of infant mortality as a key metric. Given that neonatal infections are estimated to be the cause of 26% of neonatal deaths worldwide, such a metric would help capture the quality of neonatal sepsis care and identify centers that require additional training and resources in order to improve care delivery (21).

- **Incentivized folic acid supplementation.**

We recommend the creation of laws and incentives to alleviate NGOs' difficulties in entering the country, and to provide financial support for education and supplements. Additional funding or subsidies from the government may be implemented and encouraged where NGO support may not be available.

- **Recommend mandatory folic acid fortification.**

The World Health Assembly resolution 63.17 recommended Member States “to increase coverage of effective prevention measures including vaccination against rubella, folic acid supplementation [...]” (25, 26). We highly recommend legislative support for mandatory fortification of foods, particularly flour. Fortification of foods leads to a decrease of SB, but many countries have yet to approve mandatory fortification through government legislation (27). Flour fortification is recognized by WHO, CDC, and UNICEF, (10,11,12) but as of July 2013, only 74 countries around the world had legislation to fortify at least one type of commonly consumed wheat flour with folic acid. Twenty-one of these countries are located in Africa (28). It has been shown that SB is significantly more common in world regions without government legislation enforcing full-coverage folic acid fortification of food supply, and that mandatory folic acid fortification resulted in a lower prevalence regardless of the type of birth cohort (27).

- **Government supported education is crucial to a National Prevention Campaign.**

Funding and legislation from the government to support public education about SB and its causes is essential for the primary prevention of SB. Mandatory training for healthcare workers during their training should also be supported by the government.

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SECTION 3:

PREHOSPITAL CARE

INFRASTRUCTURE

- Recommend following the WHO Emergency Care System Framework to achieve safe and prompt prehospital care.
- Prioritize effective referral networks, safe roads, and comprehensive ambulance systems.
- Strengthen multi-sector coordination and develop affordable transportation by reducing barriers and prioritizing emergency vehicles.

WORKFORCE

- Educate parents, caregivers, midwives, obstetric/gynecology, primary healthcare providers, and community workers on how to identify neonates and infants with SB/HCP, as well as complications of surgical care, and promote early referral to local tertiary care centers.
- Educate personnel or ambulance systems involved in transporting patients on where to refer patients and proper supportive emergency care.
- Interact with family support groups, and advocacy groups to increase public education and awareness.

GOVERNANCE

- Consider establishing self-sufficient pre-hospital emergency service teams at all levels.
- Consider legislation around disability rights with the aim of increasing social support and decreasing the stigma around SB/HCP and other neurologic diseases.

SERVICE DELIVERY

- Recognize the importance of public health campaigns to raise awareness, and decrease the stigma of having a child with this health problem or with a disability.
- Strengthen coordinated ambulance dispatch centers.

INFORMATION MANAGEMENT

- Optimize referrals, including creation of an alert system.
- Strengthen data collection capacity to gather information on whether a patient was referred emergently or non-emergently as well as collect data from the time of identification of SB/HCP to the time of presentation.
- Support the development of communication systems.

FINANCING

- Recognize inadequate finances as a barrier to presentation to medical facilities for patients with SB/HCP in LMICs.
- Try to provide affordable means of transportation for patients.



SOCIAL, LOGISTICAL, FINANCIAL, AND INFRASTRUCTURE INTERVENTIONS CAN REDUCE DELAYS TO REACHING CARE.

INFRASTRUCTURE



- **Recommend following the WHO Emergency Care System Framework to achieve safe and prompt prehospital care.**

Poverty, poor infrastructure, and a scarcity of hospitals equipped to quickly and competently treat SB/HCP result in obstructed access to care for affected children (1). Residing at further distances from specialized surgical centers frequently results in delayed presentation (2).

Improving transportation and reducing parental concerns about consulting medical facilities result in an increase in the identification and registration of cases (3). We support the WHO Emergency Care System Framework to assure safe and prompt presentation to care centers (4).

- **Prioritize effective referral networks, safe roads, and comprehensive ambulance systems.**

A well-organized infrastructure is especially important for managing emergencies. Networks for routine neurosurgical, orthopedic, pediatric, and urologic follow-up will also be required. With limited physician capacity, consider telemedicine* and mobile teams. Surgical patients should be transferred to tertiary facilities. Elective surgeries could be planned well in advance in order to reduce the surgical burden present at any one time; this is important to reserve surgical capacity for emergent cases

- **Strengthen multi-sector coordination and develop affordable transportation by reducing barriers and prioritizing emergency vehicles.**

We recommend strengthening multi-sector coordination and integration to reduce barriers to transportation such as affordable transport, or giving priority to emergency vehicles or those with children. Encourage community engagement for improvement of ambulance services.

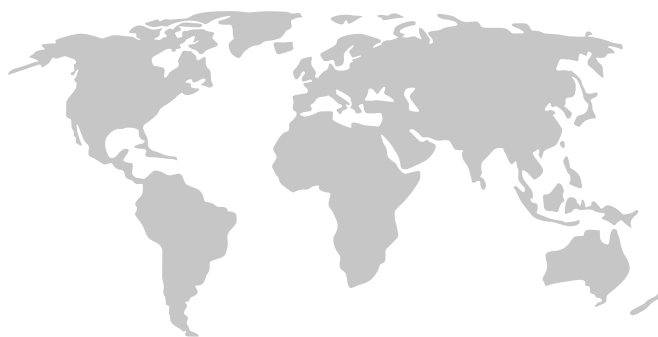
*Definition of telemedicine by the WHO: "Global Strategy on digital health" published in 2021: "The delivery of health care services, where distance is a critical factor, by all health care professionals using information and communications technologies for the exchange of valid information for diagnosis, treatment and prevention of disease and injuries, research and evaluation, and the continuing education of health care workers, with the aim of advancing the health of individuals and communities."

WORKFORCE



- Educate parents, caregivers, midwives, obstetric/gynecology, primary healthcare providers, and community workers on how to identify neonates and infants with SB/HCP, as well as complications of surgical care, and promote early referral to local tertiary care centers.

Parents, caregivers, midwives, obstetric/gynecology, primary healthcare providers, and community workers are the primary targets of education campaigns to identify neonates and infants with SB/HCP. Developing family/parental support and advocacy groups may be beneficial to increase awareness. A majority of deliveries at various health facilities are discharged home without proper counseling or referrals, and home births account for up to 25% of SB/HCP cases in LMICs (2). In Nigeria, mothers who have completed a higher level of education tend to request and receive a higher rate of surgical treatment for their children affected with SB (3).



- Educate personnel or ambulance systems involved in transporting patients and proper supportive emergency care.

Patients who present to tertiary care centers in Nigeria have at least one medical contact who facilitated the referral (3). Consider training local healthcare workers to facilitate urgent referrals (5).

- Interact with family support groups and advocacy groups to increase public education and awareness.

Mortality rates for children with SB/HCP were lower in districts where designated community workers performed regular home visits to check in on children and families, assess medical and nutritional needs, and encourage neurosurgical follow-up (1).

The aim is timely systematic and appropriate referral practices. To achieve this, national checklists and protocols for referral are encouraged, so that the flow of patients and information between different facility levels is appropriate (6).

As SB/HCP are chronic conditions, local healthcare workers should also be trained in routine care including physical and occupational therapy, catheterization, and bowel regimens.

SERVICE DELIVERY



- **Recognize the importance of public health campaigns to raise awareness and decrease the stigma of having a child with this health problem or with a disability.**

The inequality experienced by individuals with disabilities must be addressed at a societal level to improve long-term outcomes for patients with SB/HCP (5). The majority of children with SB/HCP in LMICs do not present to facilities for treatment, largely due to the cultural and psychosocial implications of having a child with a disability (1). A study in Nigeria found that a majority of mothers lacked a biomedical understanding of SB/HCP, and up to a third attribute the symptoms to witchcraft. Thus, mothers tend to feel heavily burdened by their child's care, and affected children are often lost to medical follow-up (1). In some LMICs, up to half of mothers whose children were born with SB/HCP were abandoned by their husbands (1). In an effort to reduce stigmatization of these conditions, and thereby decrease time to presentation, countries are encouraged to educate community members and healthcare workers regarding congenital lesions, causes, treatment options, and successful outcomes with the appropriate standard of care (2,5,7).

Due to the significant resource requirement of managing SB/HCP and the implications of life-long disability, families of those affected often bear a significant financial burden. To provide relief for both patients and their family caretakers, governments might consider securing social services and work programs for those with disabilities resulting from SB/HCP.

It is recommended that preventative care remains a focus of these campaigns. For example, prevention campaigns providing adequate folate intake for women of child-bearing age may help reduce the incidence of SB/HCP (8).

- **Strengthen coordinated ambulance dispatch centers.**

Recent experience suggests a well-coordinated system of ambulances dispatched by a central command has been beneficial for rapid access to healthcare. This mechanism avails itself to the nearest opportunity to offer urgent services.

Ambulances equipped with Global Positioning Systems are able to respond more quickly, and the central command centers can be supported by a medical doctor. With this system, a patient in need of urgent support can be remotely guided by the medical doctor.

FINANCING



- **Recognize inadequate finances as a barrier to presentation to medical facilities for patients with SB/HCP in LMICs.**

Patients delay presentation due to poverty and are more likely to present in a more timely manner when receiving financial support from the government or an NGO (2).

- **Try to provide affordable means of transportation for patients.**

Caregivers with sufficient financial means are more likely to present to a tertiary center in time to have surgery within 48 hours after birth (5).

INFORMATION MANAGEMENT



- **Optimize referrals, including creation of an alert system.**

Delayed presentation can increase morbidity and mortality (2). Children in LMICs who undergo surgery within two days after birth have better outcomes while mortality for children undergoing surgery 15-29 days after birth is significantly higher (5). Identifying areas with high percentages of patients presenting in delayed fashion can allow for targeted intervention to decrease referral time and improve outcomes.

- **Strengthen data collection capacity to gather information on whether a patient was referred emergently or non-emergently as well as collect data from the time of identification of SB/HCP to the time of presentation.**
- **Support the development of communication systems.**

A well-established communication system might improve resource utilization and facilitate earlier referral where needed.

To further reduce time to surgery, it is important that surgical centers track time from initial symptom to presentation, how patients are identified in the community, and what prompts presentation.

This knowledge could be used to initiate targeted interventions with the aim of reducing delays. The importance of collecting, validating, and analyzing data, on both individual patient level, facility level, and on aggregated population level could be a prioritization for governments and MOH (9). All patients that present to surgical centers should be asked about what factors may have delayed presentation after initial symptoms. The signs and symptoms at presentation, as well as outcomes, should be rigorously collected. Ideally, data collected at local healthcare centers will be collated into a central record at the tertiary care facility. This data can be used to evaluate the following: effectiveness of care and/or local caregiver training at the local centers, epidemiological trends, variations in SB/HCP patient population density, and gaps in medical personnel access.

The global success of the Health Information Systems Program is an example demonstrating a *“sustainable and scalable research project enabling and supporting health information systems implementation in more than 100 developing countries”* (9). Health Information Systems Program and its software; District Health Information System 2 provides a free and integrated software platform permitting possibilities for improved decision making on multiple levels. For patients with SB/HCP, who often require lifelong follow-up (10,11), the application of digital systems facilitating continuity of care is essential.

GOVERNANCE



- Consider establishing self-sufficient pre-hospital emergency service teams at all levels.

Recognize that a well managed emergency care and routine follow-up system in-country is an essential part of a robust health system.

To ensure safe, sufficiently regulated, and legal practice of traditional medicine, we recommend that governments clarify the role that traditional medicine may encompass within the healthcare system (12). Government support reduces time to presentation, specifically through direct financial assistance (2).

- Consider legislation around disability rights with the aim of increasing social support and decreasing the stigma around SB/HCP and other neurologic diseases.

Children with birth defects, neurological diseases, and other serious conditions who live in poverty, in remote regions, or in the midst of political turmoil do not receive the specialty medical care they require (1). In Brazil, federal law provides minimum monthly income for people with physical disabilities and financial difficulties (13).

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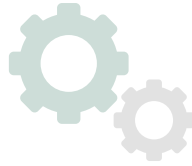
SECTION 4:

SURGICAL SYSTEM



INNOVATION AND FLEXIBLE ROLES IMPROVE ACCESS TO SAFE, AFFORDABLE, AND TIMELY SPECIALIZED SURGICAL AND ANESTHESIA CARE.

INFRASTRUCTURE



- **Develop essential and emergency surgical services, including anesthesia and obstetric/gynecology specialties for SB/HCP as integral parts of health systems.**

Shunting for hydrocephalus is recognized as one of the 44 essential surgical procedures identified by the Disease Control Priorities. Essential surgical procedures are defined as surgery that “*address substantial needs, are cost-effective and can feasibly be implemented*” (1).

Referral level hospitals should strive to provide surgical and anesthesia services for a wide range of specialties, including neurosurgery, orthopedics, pediatric surgery, and urology.

The complex nature of SB/HCP necessitates that patients receive medical care across a variety of disciplines and from a diversity of professions. A multidisciplinary team is necessary to adequately address the medical needs of these conditions (2,3). Multidisciplinary clinics most commonly include specialists from neurosurgery, orthopedics, pediatric surgery, pediatric urology, physical therapy, social work, rehabilitation, orthotics, and wheelchair management (2). Surgical care begins with myelomeningocele closure and assessment of HCP (3).

Special reference is made regarding anesthesia readiness as recommended by the World Federation of Societies of Anesthesiologists (WFSA) in 2017 (4).

- **Attempt to locate surgical and anesthesia facilities so that 80% of the population can reach them within two hours.**

The Lancet Commission recommends that 80% of the population live within two hours of a facility capable of performing the Bellwether procedures (5). Early closure of SB is recommended to reduce the risk of infections. For the case of HCP, a shunt failure constitutes a neurosurgical emergency, and treatment needs to be immediate. Therefore, it is recommended that district hospitals capable of performing initial triage and management for SB/HCP care are readily available.

- **Expand essential and reliable referral systems from first-level hospitals to ensure adequate access to care.**

A qualitative study of Zambian women who had recently given birth to a child with a NTD found five major themes in barriers to care: access to healthcare, access to transport, access to information, concerns about family, and support needs (6). These barriers can and should be mitigated at first-level hospitals prior to discharge or transfer to higher level institutions. To function effectively, first-level hospitals need at minimum a workforce trained with the understanding, and ability to recognize signs and symptoms of SB/HCP. According to the Spina Bifida Association (SBA) Guidelines: “*Care coordination (also described as case management services) in the case of people with spina bifida and their families, is a process that links them to services and resources in a coordinated effort to maximize their potential by providing optimal health care. However, care coordination for people with spina bifida and their families can be complicated due to the medical complexities of the condition and the need for multidisciplinary care, as well as economic and sociocultural barriers to coordination of care. Care coordination is often a shared responsibility by the multidisciplinary spina bifida team. Care coordination is an essential part of the multidisciplinary spina bifida care team and is vital to improving the healthcare and wellness outcomes for people living with spina bifida*”. It is recommended that SB care programs dedicate the necessary financial resources and fund sufficient full-time equivalent staff so that optimal care coordination can be provided by designated, trained, and paid healthcare professionals. It is recommended that this occurs at first, second, and third-level hospitals for appropriate and knowledgeable referrals (3).

WORKFORCE



While we use the term pediatric neurosurgeons as the cadre of surgical care providers for managing SB/HCP in high-income countries (HICs), in LMICs, specialized surgical care for these conditions are delivered by a variety of cadres, such as general surgeons and pediatric surgeons. Strategies for workforce expansion in LMICs should not unnecessarily create new categories of surgical specialists but rather aim to leverage existing divisions of labor in delivering care.

- **Studies recommend increased pediatric neurosurgical workforce (along with anesthesia support) is needed to help manage the SB/HCP population.**

Although there are an estimated 2,297 pediatric neurosurgeons practicing globally, the vast majority of these individuals (86%) reside in high-and upper-middle income countries. In low-income countries, there is approximately one pediatric neurosurgeon per 3.6 million children and it is accepted that some services may be provided by other trained surgical specialists (7).

In an international survey of neurosurgeons, it was reported that 88% of HCP consults, and 75% of NTDs required surgical intervention (8). The rough prevalence of HCP and NTDs are 740,305 and 6,695 respectively (9). Following the formula described by Corley et al., and estimating that the global pediatric population is approximately 26% of 7.53 billion, there needs to be an increased pediatric neurosurgical workforce going forward (10). In addition, improving anesthesia capabilities are supported by the WFSA, as suggested in the literature (11-13).

- Consider the establishment of dedicated training centers for the treatment and care of SB/HCP patients to address the workforce deficit.

Training centers are imperative to increase the workforce of surgeons, anesthesia providers, and nurses who can deliver essential pediatric surgical and anesthesia care. In practice, these training centers could assume many forms, including adopting the twinning program model; for LMICs, they may look like partnering with experienced centers, partners or other resource-backed institutions (14–17). Dewan and colleagues in subspecialty pediatric neurosurgery training: a skill-based training model for neurosurgeons in low-resourced health systems, describe a short term fellowship, where fellows from LMIC's spend eight weeks at Cure Hospital in Uganda and learn skills for endoscopic third ventriculostomy (ETV) among other essential pediatric surgical skills.

These surgeons then return back to their countries with an endoscope and treat children with HCP, while keeping a shared database (18). The results are promising, as many surgeons have added new skills to their repertoire and HCP is being treated with ETV's all around the world. Investment in similar programs is imperative to address the workforce deficit for SB/HCP management. Another way of improving competencies within neurosurgical care and treatment is through bilateral, long-term institutional health partnerships (19).

- Consider partnering/strengthening/supporting surgical and anesthesia providers performing treatment of HCP and SB repair as a strategy to expand services.

The WHO supports that task shifting is safe and efficacious in the right clinical settings (20). Task shifting has been shown to be an effective way to increase medical, surgical, and anesthesia capacity in a given community (21–25). Neurotrauma care is no exception; Robertson and colleagues recommend that the task shifting trainee should have obtained a degree in medicine and either completed, or be currently enrolled in a surgical training program, prior to beginning neurosurgical task shifting training.

The aim should be to optimize a pragmatic plan for workforce expansion. While training of future specialized surgeons is favored, this may be done in parallel with task sharing (preferably rather than task shifting) (26).

Task shifting – refers to a process of delegation or rational distribution of tasks among health workforce teams. Specific tasks are moved, where appropriate, from highly qualified health workers to health workers with shorter training and fewer qualifications to make more efficient use of the available human resources for health.

Task sharing - refers to an expansion of the levels of health providers who can appropriately deliver health services. Tasks are not taken away from one cadre and given to another, but rather that additional cadres are given the capacity to take on identified tasks.

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Competency-based evaluation and local supervision are essential to ensure maintenance of skills and competencies. Proper referral networks can be established for complex cases and complications to allow for tele-consultation, and physical transfer of patients when necessary. Importantly, institutions benefit by providing task-sharers with a clear definition of their scope of practice, appropriate financial compensation, and opportunities for career progression (27).

Task sharing or task shifting for cases of SB/HCP has demonstrated some success; Cairo and colleagues describe a series of pediatric patients with HCP that were managed by one general surgeon in Congo. Ninety-seven percent had ventriculoperitoneal shunt placed and had complications rates comparable to what is described in the literature for neurosurgeons (28).

Many graduates of the Cure Hydrocephalus and Spina Bifida (CHSB) Fellowship Program come from general surgery backgrounds and are exposed to a wide variety of cases while undergoing task shifting training, including SB/HCP (18).

The Cure training model exemplifies the utility of task shifting in producing a competent neurosurgical and anesthesia workforce able to help meet the growing demand in LMICs.

- **Concurrently, scaling up non-surgeon health professionals where possible, including those in the fields of pediatrics, anesthesia, radiology, nursing, social work, physical therapy, and occupational therapy as these are necessary to tackle the global burden of SB/HCP.**

Given the complex management required for these patients, particularly SB, a multidisciplinary team is required for appropriate treatment (3,22,29). These teams include surgical and anesthetic providers, pediatricians, radiologists, nurses, urologists, social workers, physical therapists, and occupational therapists among others. Reiterating the importance of these teams, the SBA “recommended that spina bifida care programs dedicate the necessary financial resources and fund sufficient full time equivalent staff so that optimal care coordination can be provided by designated, trained and paid health professionals” (3). To ensure effective team functioning, it is recommended that a nursing coordinator be used to coordinate efforts from all treatment teams and be the point person for patients and families (3,29-31).

SERVICE DELIVERY



- **Develop multidisciplinary teams and high dependency care units for the management of SB/HCP where possible.**

At birth, children with myelomeningoceles may need to be admitted to the intensive care unit or a high dependency unit (32). The importance of developing clinical guidelines that are relevant in low resource contexts may be emphasized (5). Patients delivered at outside facilities should be transferred emergently for specialized care.

A child with SB/HCP may need specialized care or intensive care nursery, often available in high-volume centers with a more dedicated team.

- **Consider dedicated wards for SB/HCP patients.**

It may be beneficial that patients with SB/HCP are located in separate wards to center the clinical competence concerned with the caretaking of these patient groups.

Emphasis on education regarding prevention, detection, and timely treatment of HCP, bladder/kidney infections, and orthopedic issues is paramount to avoid complications related to SB/HCP.

- **We recommend that hospitals that treat SB/HCP patients are provided with essential equipment where feasible.**

We suggest facilities caring for patients with SB/HCP have both an endoscope and shunt supplies with the necessary capabilities (7). When possible, ETVs can be performed prior to shunt placement. Additionally there are a variety of cost effective shunts available on the market (33).

Furthermore, non-latex materials and gloves are needed to avoid potential latex-related allergies (3).

- **Optimize access to care and referral systems by coordinated use of digital health technologies, such as telemedicine, improved diagnostic capabilities, and better communication protocols.**

Digital health technologies may be utilized to deliver best-practice care for complex conditions in health centers and community-based sites (34,35). Future technologies may avail themselves to afford more accessible ultrasound and imaging in pregnancy.

In a prospective case-control study, Thapa and colleagues describe how telemedicine in the form of free-to-use apps were applied in the Neurosurgical Department at Kathmandu Medical College Teaching Hospital (36). They conclude that telemedicine and free-to-use apps were efficient, cost-effective, and reliable. Moreover, a study by Dicianno et al., found the use of the interactive Mobile Health and Rehabilitation was feasible in patients with SB, and associated with short-term reported improvements in self-management skill (34).

- **More accessibility to ultrasound and imaging facilities may improve prenatal care in pregnancy.**

Ready access to diagnostic ultrasound and other imaging facilities will aid obstetric care and help identify SB/HCP earlier in the course. This may improve prenatal care and post-delivery management, perhaps offering a more timely intervention. In certain situations, advanced programs offering prenatal closure of myelomeningocele may be developed.

FINANCING



- **Include SB/HCP care, and essential pediatric care, into universal health coverage packages where feasible.**

The original template for National Surgical, Anesthesia, and Obstetric plans calls for basic surgical service packages to be included in universal health coverage. As SB/HCP management spans each of these fields, it is recommended that SB/HCP be explicitly embedded within larger surgical packages (37,38).

- **Consider NGOs and international partnerships to support regionally specific training and capacity building for SB/HCP care.**

In many instances, NGOs play a role in funding specific initiatives. For example, the SBA funds its own operations in making guidelines, and supporting providers and patients with educational material (3). Another example is funding for fellows in the CHSB Fellowship, where financial support for the fellows comes from scholarship support via CHSB, as well as from home institutions or departments. The program as a whole is funded by Cure (18). Additionally, there are many other models of funding via collaborations with programs from HICs and the creation of twinning programs (10,39,40). Of particular interest is the work of the Reach Another Foundation in building pediatric neurosurgical capacity in Ethiopia specifically to treat SB/HCP (41).

As countries work towards surgical and anesthesia capacity building, SB/HCP should be considered an incremental cost of the whole. The ability to pay should not prevent delivery of life saving emergency services.

INFORMATION MANAGEMENT



- Consider tracking pediatric neurosurgical and subspecialty workforce (including allied health workers) with simultaneous and perioperative morbidity and mortality.

We suggest standardized national data collection for the pediatric workforce, as well as quality and safety metrics be collected and integrated into national and global tracking databases. Data elements recommended by the Lancet Commission for assessment methods are well described (37). This includes the density and distribution of surgical, anesthetic, and obstetric (SAO) providers, the number of SAO retirees and graduates, the proportion of surgical workforce training programs and accreditation, the presence of task sharing or task shifting programs, the proportion of surgical facilities offering Bellwether procedures, the number of surgical procedures done per year, perioperative morbidity and mortality, and the availability of system wide communication. The same data elements can be obtained for pediatric (neuro)surgeons and the care of SB/HCP. This would involve the density and distribution of providers and allied health professionals, as well as the number of surgical and anesthesia facilities capable of these procedures and finally, perioperative morbidity and mortality.

GOVERNANCE



- Consider dedicated SB/HCP teams with designated leadership and to build managerial capacity and infrastructure.

It is beneficial if governments assume responsibility for developing and maintaining public surgical care infrastructure, including that which pertains to SB/HCP. However, NGOs and professional societies can play a role in consulting and overseeing development. For example, the SBA has developed comprehensive clinical guidelines that can be used to develop an infrastructure and workforce (3). Additionally, international organizations such as the WHO have a role to play in the creation of clinical guidelines and support with community-based rehabilitation (42). Community-based rehabilitation was the only significant factor that determined five-year survival in infants with myelomeningocele (2).

Additionally, a permissive regulatory environment for task sharing/task shifting is needed.

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SECTION 5:

REHABILITATION

INFRASTRUCTURE

- Recommend designated rehabilitation space and resources in hospitals that treat SB/HCP patients, where possible.
- Supporting disabled friendly transportation for access to rehabilitation centers is desirable.

WORKFORCE

- Ensure rehabilitation training capacity and education is adequate.
- Training should ideally occur at different levels of education, including preventive measures and may consider task sharing/task shifting options.
- Engage family in rehabilitation care.

SERVICE DELIVERY

- Suggest that services are tailored to age group and level of disability.
- Emphasis on transitioning patients from childhood to adulthood functioning.

FINANCING

- Embed rehabilitation services into a universal health coverage package.

INFORMATION MANAGEMENT

- Accurate collection of rehabilitation outcomes data.

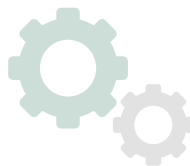
GOVERNANCE

- Encourage establishment of rehabilitation departments for long term internal sustainability.



SURGICAL OUTCOMES ARE BEST WHEN ACCOMPANIED WITH REHABILITATION. REHABILITATION SERVICES ARE INDIVISIBLE FROM SURGICAL CARE.

INFRASTRUCTURE



- **Recommend designated rehabilitation space and resources in hospitals that treat SB/HCP patients, where possible.**

The current incidence of SB in LMIC is estimated to range from 0.38 to 5.9 per 1000 live births, which is considerably higher than in HIC (1). Similarly, the incidence of new cases of pediatric HCP in LMICs is estimated to be 20 times that of HICs annually (2).

Given the known long term disability associated with both SB and HCP, rehabilitation for this population should begin from the point of initial diagnosis. For most patients, this would be in the neonatal period or infancy, in order to minimize long term adverse effects of the individual and caregivers.

Tertiary level hospitals that treat SB/HCP surgically may consider including rehabilitation services to start the process of rehabilitation as early as possible. Basic education can be provided to the caregivers at the first point of contact such that the process of rehabilitation can be started. Emphasis should be placed on achievable goals regardless of economic status. Use of advanced assistive devices that may be costly to families should be minimized.

The presence of a specialized rehabilitation center, attached to the main specialty hospital, will facilitate caregiver training and access to specialized services from the very beginning. Applying this model, patients can receive care at the hospital while parents receive training, in particular with management of incontinence and pressure sores early on. Psychosocial support is also provided by these centers, not only by the presence of professionals, but also by the community of caregivers facing these unique challenges.

- **Supporting disabled friendly transportation for access to rehabilitation centers is desirable.**

After discharge, patients often benefit from referrals to regional rehabilitation centers close to home. This will help reduce barriers for regular follow-ups and appointments to happen, as commonly reported barriers of access to care include logistical factors, affordability, knowledge, and attitudinal factors (3). In South Africa, patients are often unable to attend their rehabilitation appointments due to lack of disability friendly transportation (4).

Similar to the structure provided in the neuro-rehabilitation guidelines, it is advisable that governments also focus on providing tiers of rehabilitation centers: generalized, specialized and complex rehabilitation (5).

WORKFORCE



- **Ensure rehabilitation training capacity and education are adequate.**

There is a lack of rehabilitation professionals as evidenced by the recent statement put forth by the WHO in “Rehabilitation 2030: A Call for Action”. The estimation is that there are less than ten skilled rehabilitation practitioners per one million population in LMICs.

The aim would be for LMICs to arrive at the rehabilitation personnel capacity of HICs, which is up to 25 per 10000 population (6).

- **Training should ideally occur at different levels of education, including preventive measures, and may consider task sharing/task shifting options.**

This may include teams consisting of physicians, pediatric specialists, therapists, orthotists, orthopedic, and urological specialists.

While the ultimate aim is to ensure that there are specialized rehabilitation personnel trained for the SB/HCP population, the emphasis should be on educating a large group of general rehabilitation professionals who are also educated in basic aspects of providing rehabilitation to this specific population.

Rehabilitation education programs focusing on competencies for working in underserved contexts may be established. In addition, other health workers such as physicians, nurses or community health workers in remote settings can also be trained to acquire and apply rehabilitation competencies within their practices (6).

- **Engage family in rehabilitation care.**

Rehabilitation workers and medical professionals need to be trained to focus their teachings on the family and caregivers. Clear, easy, and achievable instructions given to the caregivers often provide better outcomes. This is especially important for patients who live in remote and underserved areas.

SERVICE DELIVERY



- **Suggest that services are tailored to age group and level of disability.**

Each age group has different needs. Therefore, rehabilitation specialists need training to respond based on the patient's age. Given the transition into adulthood and independent living is particularly important, longitudinal care should be emphasized. Deterioration often happens as age advances, which elucidates the importance of clinical follow-up across the lifespan of a patient, even in well-functioning SB patients (9).

In addition to stratification by age group, level of functioning in SB patients is also particularly important when considering rehabilitation needs. In general, the level of the lesion in SB patients is correlated with neurocognitive outcomes, and thus rehabilitation goals should be tailored accordingly (10).

Support for caregivers of patients with SB/HCP is also crucial to the rehabilitation of this population. In LMICs in particular, the paucity of rehabilitation centers has led to the birth of community-based rehabilitation programs, which have largely been successful at addressing resource constraints (11). As such, issues that affect caregivers should also be addressed and supported in order to maximize success (12).

- **Emphasis on transitioning patients from childhood to adulthood functioning.**

Service delivery of rehabilitation resources to patients with SB/HCP should begin from childhood and continue into adulthood. This model may improve care and help patients achieve a higher quality of life and maximum independence (7,8).



FINANCING



- **Embed rehabilitation services into universal healthcare coverage package.**

While there is no data directly addressing the economic burden of lack of rehabilitation for the SB/HCP populations, data indicating the economic burden of the SB/HCP population on a country exist. A study in Kenya has shown that SB carried the highest burden of disease compared to all surgical congenital anomalies, and HCP represented the greatest burden of disease amongst males (13).

Despite the economic costs sustained by this population, there is a lack of emphasis on rehabilitation, particularly in LMICs, due to resource constraints. While there are no clear studies elucidating the budget dedicated to rehabilitation of persons with disabilities, two studies from India and Philippines have shown that less than 1% of the gross domestic product is spent on the care of persons with disabilities (14).

Given surgery is cost effective for reducing the burden of disease due to congenital diseases such as SB/HCP (15), there will be a subsequent rise of patients who survive these conditions but with residual disabilities. Consequently, incorporating post-surgical rehabilitation aids neurodevelopment.

Community-based rehabilitation has been developed since the 1970s to provide maximal coverage of rehabilitation at the community level, particularly in LMICs. Commonly, NGOs will also provide rehabilitation support through grants and donations that support personnel (16). However, for long term sustainability of a program, it is crucial that funding for rehabilitation care is integrated into a universal healthcare plan that is supported by stakeholders and local governments (17).

INFORMATION MANAGEMENT



- **Accurate collection of rehabilitation outcomes data.**

Registries for birth defects, including NTDs and HCP, are more common in countries with higher incomes. However, the burden of disease is highest in countries with lower incomes (18).

Data regarding the rehabilitation of SB/HCP patients would be invaluable in advocating for essential services for this population. Ideally, rehabilitation records should also be part of the medical record of a patient. This allows providers to not only track the progress of patients, but also conduct population outcomes research.

GOVERNANCE



- **Encourage establishment of rehabilitation departments for long term internal sustainability.**

The support of the local government is crucial to the sustainability of any program, particularly in the health sector (19). Governments in LMICs countries have improved in-country mortality rates, by investing in education, sanitation, transportation, and general infrastructure (20).

We suggest rehabilitation services be regarded with the similar importance as providing vaccinations in national health plans. It is recommended that each referral hospital maintain a modest rehabilitation department as a crucial service, with emphasis on continuous medical education and quality improvement. It is essential that governments allocate a sufficient portion of the national health budget towards rehabilitation, given its importance, regardless of ability to pay (21).

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SECTION 6:

TRANSITIONAL AND FOLLOW-UP CARE

INFRASTRUCTURE

- Determine the catchment area for SB/HCP centers.
- Consider a national strategy for following SB/HCP patients across the life course.
- Consider emphasizing community-based rehabilitation and people-centered facilities, such as bathrooms with private space for self-catheterization.

WORKFORCE

- Empower nurses and community health workers to extend the reach of physicians, and augment the quality and accessibility of SB/HCP care.
- Give agency to the patient.
- Establish a referral network between transitional care coordinators and pediatric specialists, neurosurgeons, neurologists, urologists, orthopedic surgeons, social workers, nutritionists, etc.

GOVERNANCE

- Strengthen legislation to protect rights of SB/HCP patients.
- Consider having regional multidisciplinary SB/HCP teams to oversee the process.

SERVICE DELIVERY

- Safely transition patients from childhood to adulthood.
- Implement contextually relevant checklists to guide evaluation of typical associated health problems.
- Employ structured methods for transitioning pediatric patients to adult care providers.

INFORMATION MANAGEMENT

- Use quality of life metrics during follow-up visits in SB/HCP care, and ideally adopt validated tools for LMICs.
- Consider using a locally developed SHIP (Spina Bifida and Hydrocephalus Interdisciplinary Programme) system.

FINANCING

- Extend universal healthcare coverage to include transitional/follow-up care.
- Utilize a shared input and strategic model for cost allocation of transitional/follow-up care goods and services.
- Encourage a public/private partnership.



A PATIENT-CENTERED APPROACH MEANS SUPPORT THROUGHOUT THE LIFE COURSE OF PATIENTS WITH SPINA BIFIDA AND HYDROCEPHALUS.

INFRASTRUCTURE



- Determine the catchment area of SB/HCP centers.

Transitional and follow-up care coordination between the patient, family, healthcare providers, school, and allied health services enables those with SB/HCP to optimize their quality of life and integrate into society. This incorporates both the transitions between inpatient care and post-hospital care, as well as transitions between pediatric and adult care. This is particularly important for these patient populations as the life expectancy for SB/HCP continues to rise. To better facilitate care, it may be beneficial that the catchment area of a SB/HCP center is determined. With proper investment it may be possible that by age 30, approximately one-third of individuals with SB are independent, one-third need supervision and occasional help, and one-third routinely need assistance for daily care needs (1).

- Consider a national strategy for following SB/HCP patients across the life course.

Fortunately, progress within the field of medicine and rehabilitation will lead to an increase in the number of children with SB/HCP that survive into adulthood. Therefore, strategies involving transitional care across the life course need to be emphasized (2).

- Consider emphasizing community-based rehabilitation and people-centered facilities, such as bathrooms with private space for self-catheterization.

Support of community-based rehabilitation may aid families, neighborhoods, and schools, to strengthen people-centered facilities for children with disabilities, including SB/HCP (3).

WORKFORCE



- Empower nurses and community health workers to extend the reach of physicians, and augment the quality and accessibility of SB/HCP care.

Nurses and community health workers are poised to become valuable partners in efforts to improve SB/HCP care as “transitional care coordinators,” particularly during transitions between the hospital and home, or progression from pediatric care to adulthood. (Neuro)surgical transitional care programs have been shown to improve patient safety and care efficiency by investing in nurse coordinated care to assist in patient education, medication reconciliation, transfer to home, and follow-up/surveillance (4-6). These members can play an important role in educating the public about prevention issues.

Transitioning SB/HCP patients from pediatric care to adulthood, budget-neutral programs that involve nurse transition care coordinators have facilitated family-centered care plans focusing on improving self-management and readiness for transition to adulthood (7). Key features of hospital discharge programs include dedicated time for patient education prior to hospital discharge, and a follow-up phone call shortly after discharge. For longitudinal management, there was benefit to monthly contact to discuss goals on activities of daily living, surveillance of complications, appointment scheduling, and providing resources and referrals.

While SB/HCP care coordinators would not necessarily need to have a nursing certification, the transitional care coordinators would need a baseline level of training and clinical competence to ensure adequate surveillance. Furthermore, these check-ins could be performed through telecommunication to allow staff to answer outpatient questions remotely and expand program reach. Thus, we recommend an element of task sharing with nurses and community health workers for screening, physical/occupational rehabilitation, psychosocial support, and routine surveillance.

- Give agency to the patient.

Goal-setting, within transitions of care and rehabilitation is a tool to help patients make functional progress (8). This can be done through discussion, health contracts, and more recently, digital applications that allow for two-way communication between patients and providers. The interactive Mobile Health and Rehabilitation has been developed at the University of Pittsburgh to support self-care and adherence to self-care regimens for individuals with SB and other complex conditions who are vulnerable to secondary complications (9). As mobile phone technology becomes more ubiquitous, this may be used in LMIC settings. A goal-setting system uses checklists, data tracking, and fact-finding tools to empower patients and their families to play a larger role in their care (8).

Setting targets via manual or digital checklists can facilitate appointment scheduling, symptom tracking, medication compliance, and more. Continued innovation and integration of digital tools is needed to enhance patient experience and autonomy.



- Establish a referral network between transitional care coordinators and pediatric specialists, neurosurgeons, neurologists, urologists, orthopedic surgeons, social workers, nutritionists, etc.

SB/HCP patients often have delayed presentations to specialists, with 40% of patients presenting after chronic kidney disease stage 1, and many individuals presenting late for pain or shunt failure (10-12). According to a study in Argentina, healthcare teams were able to mitigate this problem by establishing a professional network (via emails and Google groups), multi-site team training, video conferences, incorporating the MOH, and establishing a telemedicine network to inform patients and empower caregivers throughout Argentina (13). Having a referral network for initial diagnoses, as well as complications such as shunt infection or failure, is critical in acute management and long-term maintenance (14).

SERVICE DELIVERY



- Safely transition patients from childhood to adulthood.

Some of the most successful service delivery advances for SB/HCP patients have been the generation of a medical home(6). This involves a team of transitional care coordinators, nurses, neurosurgeons, neurologists, pediatric surgeons, pediatric urologists, orthopedic surgeons, social workers, nutritionists, and more. Close follow-up in-person or digitally, can occur after a hospitalization with transitional care coordinators or nurses to ensure medication compliance and surveillance of complications. Issues that require more specialist input can then be triaged to the appropriate group.

FINANCING



- **Extend universal healthcare coverage to include transitional/follow-up care.**

It is well established that pediatric SB/HCP patients have lifetime medical needs that extend far beyond the acute phase of their condition (24-26). As these patients' transition to adulthood, gaps in their care can lead to future hospitalizations and poorer outcomes, which in turn places a heavy strain on the healthcare system (7). A means of mitigating the aforementioned challenges would be to broaden the universal healthcare coverage to impact transitional/follow-up care. Shared public resources can enable further skills training, transportation, and other job-specific requirements for already established community healthcare workers to effectively meet the chronic needs of SB/HCP patients. Durable medical equipment may be subsidized and made affordable to patients and their families.

- **Utilize a shared input and strategic model for cost allocation of transitional/follow-up care goods and services.**

There are several moving elements that might be accounted for in the costs of transitional and follow-up care in SB/HCP patients. Organizing and coordinating these variables in a structured manner may be helpful. To consider the costs of durable medical equipment, personnel, physical space, storage, travel time, maintenance, recurrent training, donated goods, and other services are advisable (27). Encouraging shared input from all parties in developing and executing a strategic model for an effective spending approach and cost analysis, might be made a priority.

- **Encourage a public/private partnership.**

Philanthropic donations of goods and services to underserved areas have been the focus of several large entities in the past. Successfully using this momentum to partner with interested entities to support durable medical equipment donations in the care of SB/HCP can prove to be effective as it has in other altruistic aid (28). Furthermore, on a larger scale global health resources have expanded in recent years and harkening the attention of major/minor contributors to global health programs may provide opportunities for the specific needs of pediatric SB/HCP patients transitioning their care (29).

- **Implement contextually relevant checklists to guide evaluation of typical associated health problems.**

SB/HCP patients are at increased risk for primary and secondary medical complications. Common impairments caused by SB are paraplegia and orthopedic conditions (scoliosis, clubfeet, and hip problems), neurogenic bladder and bowel, varying degrees of cognitive deficits, shunt dysfunction, pressure sores and serious infections, and more chronic sequelae from obesity, hypertension, pain and deterioration in ambulatory function. Patients and caretakers would benefit from the creation of a time-based checklist to guide evaluation of typical SB/HCP associated health problems within a chronic care model (12). While more sophisticated checklists are under development, key health domains to discuss with patients include diet, exercise, weight management, appointment scheduling, tracking needs for items such as wheelchairs or adaptive driving, vocational and school activities, pain, and sleep. It may be beneficial if patients also undergo continual assessment for durable medical equipment, rehabilitation, and evolving needs.

- **Employ structured methods for transitioning pediatric patients to adult care providers.**

Transitioning patients from pediatric to adult care providers is necessary to provide graduated autonomy to the patient over his or her care, and appropriately manage the patient's chronic conditions. This approach requires a new conceptual model for SB services (15). Successful transitions have been associated with a decreased incidence of hospital admissions and emergency visits (16). It is suggested transition planning is initiated when patients are 12-14 years of age, with the intent of fully transitioning to adult providers by age 18-21 (17).

Healthcare providers and transitional care coordinators should use objective, standardized methods to facilitate their evaluation of patient readiness for transitions. The Transition Readiness Assessment Questionnaire (TRAQ) is one widely used validated 20-item instrument, a patient-report assessment of health and self-management skills (18). It takes less than five minutes to complete and helps gauge a patient's autonomy and compliance over medication management, appointment keeping, health tracking, communication with providers, and managing daily activities (19). It is recommended that specific attention to body mass index and sexual health also be included, as these patients commonly face such challenges in later years (20-23). Different methods can be used for this assessment that are adapted to circumstances of the patient's environment. For those who do not appear ready to transition, this is an opportunity to connect the patient and family with additional resources and guidance.

INFORMATION MANAGEMENT



- Use quality of life metrics during follow-up visits in SB/HCP care, and ideally adopt validated tools for LMICs.

Identifying the efficacy of any intervention is a cornerstone to best practice management and future growth (30). Establishing quality of life metrics for SB/HCP patients is a practical step to ensure this. The SBA and the WHO have quality of life metrics for SB patients (31,32). Sick Kids at the University of Toronto has an effective quality of life metric for HCP patients (33). The self-reported health-related QUALity of Life Assessment in Spina bifida (QUALAS) has been validated in children (QUALAS-C), teenagers (QUALAS-T), and adults (QUALAS-A) and has been, and can continue to be, adapted to fit specific country needs as well (34-36). This information should be stored and available for review at the MOH.

- Consider using an locally developed SHIP (Spina Bifida and Hydrocephalus Interdisciplinary Programme) system.

Using an integrated information system to facilitate long-term communication between healthcare providers, parents/caregivers, and patients by applying a SHIP passport where all essential information about the child and the management are registered (37), is readily accessible (has shown to be effective in Tanzania).

GOVERNANCE



- Strengthen legislation to protect rights of SB/HCP patients.

We encourage programs and policies supporting the rights of persons with disabilities to be implemented and enforced. The PUSH Scorecards provide country and regional snapshots of indicators grouped by WHO regions (38). It is encouraged to sign and ratify the United Nations Convention on the Rights of Persons with Disabilities. We recommend local, regional, and national authorities ensure that individuals with disabilities have access to the care and resources they need to integrate into society, including education and healthcare.

- Consider having regional multidisciplinary SB/HCP teams to oversee the process.

Patient care is often improved by teams of providers dealing with a focused issue - patients benefit when a multi-specialty group participates in their care.

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APPENDIX I

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