



Spina bifida management in low- and middle-income countries — a comprehensive policy approach

Jogi V. Pattisapu¹ · Vigneshwar Raj Veerappan² · Colette White³ · M. V. Vijayasekhar⁴ · Nebiyat Tesfaye⁵ · B. Hayagriva Rao⁶ · Kee B. Park⁷

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Abstract

Introduction Globally, spina bifida (SB) occurs more often in low- and middle-income countries, where the healthcare demands are often quite challenging. Several social/societal issues and/or lack of government support makes for incomplete SB management in many areas. Clearly, neurosurgeons should be knowledgeable about initial closure techniques and the basics of SB management, but must also advocate for the patients outside our immediate scope of care.

Methods Recently, the Comprehensive Policy Recommendations for the Management of Spina Bifida and Hydrocephalus in Low- and Middle-Income Countries (CHYSPR) and the Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders (IGAP) publications emphasized the need for a more unified approach to SB care. Although both documents discuss other neurological conditions, they support SB as a congenital malformation needing attention.

Results We identified several similarities for comprehensive SB care in these approaches — including education, governance, advocacy, and the need for continuum of care. Prevention was recognized as the most important aspect for SB going forward. A significant return of investment was noted, and both documents recommend more active neurosurgical involvement (i.e., folic acid fortification).

Conclusion A new call for holistic and comprehensive care for SB management is recognized. Neurosurgeons are called upon to use solid science to educate governments and actively participate to advocate for better care and most importantly, prevention. Folic acid fortification schemes are mandatory and neurosurgeons should advocate for global strategies.

Keywords Spina bifida · Advocacy · Prevention · LMICs · CHYSPR · Intersectoral global action plan

Abbreviations

CHYSPR Comprehensive Policy Recommendations for the Management of Spina Bifida and Hydrocephalus in Low- and Middle-Income Countries
DALYs Disability adjusted life years

FA Folic acid
IGAP Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders
LMIC Low- and middle-income country
NGO Non-governmental organization
SB Spina bifida
WHO World Health Organization

✉ Jogi V. Pattisapu
JPattisapu@Ped-Neurosurgery.com; Jogi.Pattisapu@UCF.edu

- ¹ College of Medicine, University of Central Florida Orlando, Orlando, FL, USA
- ² Hull York Medical School, University of York, York, UK
- ³ Tulane University School of Medicine, New Orleans, LA, USA
- ⁴ Rangaraya Medical College, Kakinada, India
- ⁵ St. Peter Specialized Hospital, Addis Ababa, Ethiopia
- ⁶ Andhra Medical College, Visakhapatnam, India
- ⁷ Program for Global Surgery and Social Change, Harvard Medical School, Boston, MA, USA

Introduction

Neurosurgeons are frequently called upon to play a major role in managing conditions beyond the operative management, including helping governments determine best policy for general public health and welfare. Since spina bifida (SB) occurs more frequently in low- and middle-income countries (LMICs), this manuscript will focus on recommendations to aid policymakers manage several aspects of SB in such areas. Specifically, issues regarding service delivery, workforce, infrastructure,

information management, financing, and governance will be considered.

The prevalence of this serious condition has decreased remarkably over the past few decades to 0.2–0.4/1000 births in countries where required folic acid (FA) fortification of grains has been implemented [1]. Unfortunately, in many parts of the world, the SB incidence remains remarkably high (as high as 4 to 8 per 1000 births) [2, 3]. There is wide variance and severe involvement of SB requiring immediate attention and active participation of many groups and individuals, especially in LMICs.

A systematic review and meta-analysis by Atta et al. summarized the SB prevalence by country and FA fortification status [4]. They found that the prevalence is lower in geographical regions with mandatory versus voluntary FA fortification (33.86 vs. 48.35 per 100,000 live births or LBs) respectively. They also noted that the SB prevalence was lower in studies that examined all birth outcomes (i.e., LBs, stillbirths, and terminations of pregnancy) in regions with mandatory versus voluntary fortification (35.22/100,000 vs. 52.29/100,000 LBs). The pooled SB prevalence significantly greater was in LMICs, since many lacked SB tracking or surveillance systems (limiting understanding of its burden, including mortality) [4–6]. There is a need for immediate attention to these severe and life-threatening birth defects that largely go unnoticed by policy makers. Active participation of several organizations is warranted to ensure babies born with SB receive needed care and rehabilitation.

The Comprehensive Policy Recommendations for Spina Bifida and Hydrocephalus (CHYSPR) was recently published, led by the Harvard Program in Global Surgery and Social Change in conjunction with the International Society for Pediatric Neurosurgery (ISPN) and other organizations. Almost simultaneously, the Member States of the WHO adopted the Intersectoral Global Action Plan for Epilepsy and Neurological disorders (IGAP) in May 2022. These two documents frame the recent energy and momentum regarding SB and the potential for better care and eventual global prevention efforts.

The global incidence of SB has been declining over the past few decades, mostly due to improved medical care globally and folate acid fortification (mandatory in approximately 80 countries) [7, 8]. However, there is a significant global burden with almost 300,000 babies born each year, often in underdeveloped and resource-challenged areas [9, 10]. This estimate is the best available, mainly because of limited data regarding incidence, prevalence, and potential termination before medical care.

Even now, many countries offer termination of pregnancy soon after SB diagnosis and even late into pregnancy [11]. True incidence is therefore difficult to ascertain since many women undergo pregnancy termination before such data can be tabulated. Similarly, the high incidence of infant

mortality in various countries could also be due to SB or similar congenital malformations (details regarding cases are also limited). In many areas, adequate prenatal care and management are unavailable, in addition to lack of knowledge regarding management of newborn meningomyelocele defects, etc.

Education and clinical management

Education regarding proper closure techniques, preferably using a complete 3-layer closure, is necessary. The anatomy of a fresh neural tube defect is somewhat complicated, and some surgeons simply close the skin without attempt at proper neural tube reconstruction or a watertight dural closure with competent skin covering. Neurosurgeons may offer such education by telemedicine or virtual conferencing combined with in-person and direct hands-on training when necessary. Such educational efforts must be headed by neurosurgical team members in an organized format/structure. Consistent and repetitive training sessions for the workforce are needed to maintain knowledge and skills.

The development of a complex SB clinic and resource center is very important in the management of SB babies and patients. Adequate resources are mandatory to maintain such a teamwork of committed individuals and experts, which often yields better outcomes and lifestyles for SB patients. Multimodal care of this nonlethal condition should be nurtured and developed so that patients can attain their full potential (albeit with some limitations).

The multidisciplinary SB clinic often includes members from neurosurgery, orthopedics, urology, pediatrics, developmental medicine, occupational therapy, physical therapy, and social work etc. Such a comprehensive team offers the best care and potential for the good outcomes in the long term. While such a coordinated care network is not yet possible in most LMICs, similar efforts may be established with dedication and relatively few resources (possibly using telemedicine or video conferencing). Specialists from afar can participate in patient care and offer opinions without the burden of travel. This option is utilized more often since the COVID-19 pandemic, and most centers have adopted a hybrid model to extend their resources successfully. Patients might benefit from a dedicated SB team discussion approach regarding various issues and potential options.

Along these lines, a well-structured transition program helps young individuals as they progress to adulthood. In most situations, SB care is rather abruptly discontinued (or not coordinated), causing significant confusion and delay. Often, this involves a urologic concern (such as clean intermittent catheterization) and adult orthopedic or neurosurgical issues. Many patients suffer due to this disconnection and ineffective communication, with relatively few resources available to maintain a good transition program in most situations.

Social integration has always been an issue for SB patients, especially in LMICs or resource-limited areas. The stigmata of paralysis or bladder difficulties are permanent concerns, and education can offer a possibility for effective entry into society. Handicap access and workplace limitations make it very difficult for the adult SB patient to enjoy gainful employment in most countries. If they can be initiated, governments will benefit in the long term by assisting SB patients assimilate into social programs for integration and self-sustenance. Over the long run, these options may save precious resources with less overall dependence, since some patients may return to work and support the economic machine.

Prevention is the utmost important factor in SB care. More so than excellent surgical skills, wonderful post-operative care, or well set up treatment systems, prevention is the key in most countries. With relatively little resources, significant return on investment can be obtained by FA fortification of staple foods, especially reaching all women of reproductive age in LMICs [12–14]. There has been a notable global reduction of SB prevalence proving the effectiveness of fortification policies consistently in different populations [4, 15, 16]. FA fortification policies have been safe, and there has been no evidence supporting adverse effects from these efforts [17].

As neurosurgeons, we have a pivotal role in promoting advocacy and supporting governmental organizations and non-governmental organizations (NGOs) towards the goal of universal FA fortification of staple foods. Our voice must be based on strong scientific data and be clear and unified in purpose. Together, we can make a positive effort to change prevention policies in countries where needed and convince the policy makers about the benefits of promoting health and preventing death and disability. The neurosurgical community can help universal FA fortification by communicating the need and urging their Ministries of Health to support the WHA resolution put forth by the Columbian Health Ministry in 2022 [18]. Such views are echoed in recent publications, and several groups have called for action to implement universal mandatory fortification programs [7, 8].

Recently, new efforts have gained momentum that bring together support from Rotary Clubs, Lions Clubs, Kiwanis International, etc. Together, these organizations have over 3.8 million members, with active prevention measures and awareness campaigns to quickly obtain significant energy. Such collaborations have proven useful in the fight against polio several decades ago. Similar efforts are again underway, and neurosurgical input and support are most crucial to this work [19].

CHYSPR — actionable points for neurosurgeons

In November 2021, the Comprehensive Policy Recommendations for Spina Bifida and Hydrocephalus, (CHYSPR) was published, led by the Harvard Program in Global Surgery and Social Change in conjunction with the International

Society for Pediatric Neurosurgery and other organizations. The document provided a broad and comprehensive surgical care outline for SB and hydrocephalus, divided into 5 sections. These are (1) Screening/surveillance, (2) Prevention, (3) Pre-hospital care, (4) Surgical systems, and (5) Rehabilitation and Transition/follow up care. Each section is presented in terms of 6 health systems building blocks: (a) infrastructure, (b) workforce, (c) service delivery, (d) financing, (e) information management, and (f) governance.

Comprehensive SB care requires support from many specialties/healthcare professionals, general public, governmental agencies/policy makers, and NGOs. CHYSPR includes the entire care pathway from prevention and screening to rehabilitation and follow up and across all levels of care from community to tertiary care. It discusses evidence-based recommendations within clinical environments and others to address the SB burden. While the CHYSPR document is aimed at a diverse audience (ranging from advocates, clinicians, and policy makers), we hope to emphasize certain concepts for neurosurgeons dealing with SB in LMICs.

Changing clinical practice

Neurosurgeons can change their clinical practice to better serve SB patients in multiple ways, beginning with education and team building. Such actions help coordinate efforts and focus the team towards better patient care while developing other opportunities (such as advocacy and prevention). We should advocate for and work toward building multidisciplinary teams (i.e., pediatricians, specialists, nurses, intensivists, anesthesiologists, and therapists). With education, the SB team can perform a more thorough physical examination to document the findings for long-term care or research studies [20]. Moreover, neurosurgeons can help improve training, education, and services across the spectrum of SB care from district to tertiary-level hospitals, since we recognize the expertise required at different stages.

It is equally important to include patients and families through decision-making steps, to provide more agency over their care [21]. This can be further aided through the implementation of mobile technology, allowing patients ease of access to their health information. E-consultation platforms and video teleconferencing also enable remote follow up, providing easier access to post-operative care from remote areas [22]. Finally, neurosurgeons can implement frameworks such as the WHO emergency care system framework to improve SB management [23].

Workforce capacity

Upscaling of healthcare workforce is needed to address the SB burden and requires action to increase capacity and

capability (by qualified pediatric neurosurgical training). International partnerships and exchange programs where short-term focused training in particular skills can facilitate this process [24]. Moreover, implementation of innovative technologies such as virtual reality and simulation training can improve the quality of training in a cost-effective way [24, 25]. Easily accessible and low-cost video conferencing have enabled interactive education much more accessible, where trainees are able to learn from global neurosurgical experts through regular teaching sessions such as virtual grand rounds [26]. The ISPN Guide and routinely conducted courses are excellent resources among many offered by pediatric neurosurgeons globally.

Until the existing neurosurgical shortage can be addressed through formal training, task-sharing or task-shifting initiatives may be considered. Other healthcare professionals may carry out simple, specific procedures independently and in a safe manner, allowing the limited neurosurgeons to manage more complex issues [27]. Although not universally accepted, trained healthcare professionals with limited expertise may provide care in remote areas, enabling specialists to focus on more complex issues. These models have been undertaken safely, yielding positive preliminary results and reducing overall neurosurgical burden [27–31]. Task sharing and task shifting can be incentivized by accreditation through international organizations, providing professional motivation. Additionally, neurosurgeons and colleagues can establish specialized clinics, wards, or hospitals for SB care, which can serve as centers for focused care and specialist training [32–34].

Neurosurgeons should also advocate for improving access to non-neurosurgical services such as obstetrics, prehospital care, pediatrics, and ancillary services. We should work to improve SB education and training within those specialties and develop the next generation of multidisciplinary teams [35–38].

Building research capabilities

Research is an important component of SB care, and neurosurgeons can have a profound impact by spearheading local academic efforts (demonstrated by regional centers such as Andhra Medical College, Visakhapatnam, India). Building research capacity involves the nurturing of an educated/dedicated workforce while supporting an infrastructure for data collection and management systems [19, 39]. This multidisciplinary research team should be diverse, including medical students, trainees, junior faculty, and other specialists. They can be encouraged to participate in various research initiatives in roles such as data collection and analysis, providing them with early exposure to comprehensive SB care and academic pursuits. Research infrastructure is more complicated to upscale as it requires funding, governance, and

administrative support from local institutions. Collaborating with international organizations enables neurosurgeons to leverage their research workforce, expertise, and infrastructure, possibly identifying extramural funding opportunities.

Research forms as integral component of SB care and provides an opportunity to track the overall burden locally. These data can provide details regarding epidemiology, peri-operative morbidity and mortality, workforce mapping (neurosurgery and allied healthcare professionals), and barriers to accessing care and the impact of any intervention [40–43]. Neurosurgeons and research groups can also use this information to set targets or measure progress at national or international standards. With such data, governments can be informed if certain targets are met adequately (such as ensuring 80% of the population is within 2 h of SB care as outlined in the Lancet Commission for Global Surgery [43].

As neurosurgeons lead the establishment of local research groups, we can also build a network with other efforts towards national registries. Such efforts will eventually improve resource utilization and will require standardization using common data elements [41].

Advocacy for spina bifida care

It is important that neurosurgeons are strong advocates to inspire and motivate action toward reducing the adverse effects of SB [8, 19]. Advocacy is the most effective when supported by ample high-quality evidence and done collectively with other local healthcare professionals or global epidemiology or public health experts. Hence, championing this effort often follows research, and establishing local/national data registries helps academic advancements while providing a strong advocacy tool to lobby politicians/governments into action [40]. As such, neurosurgeons can add a strong voice to the efforts and momentum driven by many NGOs.

Several options for advocacy are available for the neurosurgeon — we can advocate for more funding for prevention, screening, management, rehabilitation, and follow up care. As described above, primary prevention strategies involving mandatory FA fortification of staple foods are overwhelmingly effective in reducing SB prevalence [9, 44]. Currently, more than 80 countries have implemented this strategy, and recently, the Columbian Ministry of Health put forth a proposal to the World Health Assembly towards mandatory global fortification [K. Ghotme, personal communication]. In Ethiopia, neurosurgeons had a very prominent role in encouraging their government to make FA fortification of wheat flour mandatory [9, 45].

Neurosurgeons can also advocate for stronger healthcare referral systems and increased funding for public education or awareness campaigns [41]. Besides the governments, we can also advocate for NGOs to fill in strategic gaps in the healthcare systems. Public education and awareness

have many benefits including seeking early healthcare, de-stigmatization of the condition, and reduced social isolation [46, 47]. Such efforts also enable pro-active action in SB research, registry advocacy campaigns [48].

Neurosurgical perspectives and IGAP 2022–2031

The Intersectoral Global Action Plan for Epilepsy and Neurological Disorders 2022–2031 (IGAP) (in consultation with member states) addresses challenges and gaps in providing care and services globally. In this document, the term “neurological disorders” is used to denote conditions including neurodevelopmental conditions, such as SB. This action plan is aimed towards decreasing the global issues with epilepsy and other neurological disorders and ensures a comprehensive, coordinated response across sectors [49].

First and foremost, IGAP promotes raising neurological disorders to a higher priority within governments and stresses the resulting proven long-term return on investment. With a multidisciplinary approach where prevention, diagnosis, and treatment are adequately fostered, a high standard of care is possibly achieved eventually. From a neurosurgical standpoint, this requires education, task sharing/shifting, strengthened referral systems, and specialty training in the context of limited resources.

IGAP represents a subset of the information and reporting needs that member states require to adequately monitor their policies and programs for neurological disorders. Given that targets are voluntary and global, member states are not necessarily expected to achieve all the specific targets individually but can contribute to a varying extent towards reaching them jointly.

The Secretariat will provide guidance, training, and technical assistance to Member States for the development of national systems to capture global data. Indicators of neurological health systems, activities, and outcomes will be collected with the aim of building on existing information, rather than creating new or parallel systems. One of the global targets relevant for prevention of neurological disorders includes an action plan to end preventable deaths in the newborn. SB causes significant infant mortality and may not be captured in current data systems since often listed as infection or cardiorespiratory arrest.

Here, we emphasize IGAP Strategic Objective 3: To implement strategies for promotion and prevention, and some of its key features for LMICs (including some Global Targets).

Global target 3.1 Globally, 80% of countries will have at least one functioning intersectoral program for brain health promotion and prevention of neurological disorders across the life course. IGAP further emphasizes that many neurological conditions are preventable, including SB and other congenital disorders.

Global target 3.2 The global targets relevant for prevention of neurological disorders are achieved, as defined in the:

- The Non-Communicable Diseases-Global Action Plan 1 (NCD-GAP1), with plans to defeat meningitis by 2030 (SB deaths are often due to meningitis in the perinatal period).
- NCD-GAP2 — Every newborn: an action plan to end preventable deaths (which includes SB, often a frequent cause of infant mortality in LMICs).

Global target 4 focuses on research and aids LMICs to develop systems for data mining, storage, and analysis, as to provide support for effective governmental decisions. (similar to CHYSPR).

Alignment of CHYSPR guidelines and WHO IGAP (Fig. 1)

Although CHYSPR is focused on SB and hydrocephalus, while IGAP is focused on neurological conditions such as epilepsy, both these documents share several commonalities and can be synergistically viewed and acted upon by neurosurgeons. Each encourages governmental support for several neurological issues, and we describe below the similarities aimed to improve SB, epilepsy, and other neurologic disorders.

1. While CHYSPR focuses on SB prevention, prehospital care, surgical systems, rehabilitation, and follow up care, IGAP strives to prioritize and strengthen governance for neurological disorders in general, specifically for epilepsy.

Both documents lay out a comprehensive framework for neurosurgical and neurological conditions outside of SB and epilepsy. Developing multi-disciplinary teams/specialized treatment centers for SB will likely improve care of other neurosurgical conditions, setting a precedence for specialized treatment centers through improved financing and governance.
2. Both CHYSPR and IGAP recognize the role of advocacy in developing care for neurological and neurosurgical conditions. Establishing a complex care model is multi-faceted, requiring resources and staff, appropriate health system structures, funding, and public prevention strategies at regional and national levels. These require political will, neurosurgical input/support to convince policy makers, and other healthcare professionals.
3. Both emphasize the public health component in the treatment of neurological and neurosurgical conditions. Focusing on SB, CHYSPR recommends strengthening infrastructure, workforce, service delivery, financing, data management, and governance, while IGAP strives to improve timely diagnosis and treatment and care for several neurological disorders.

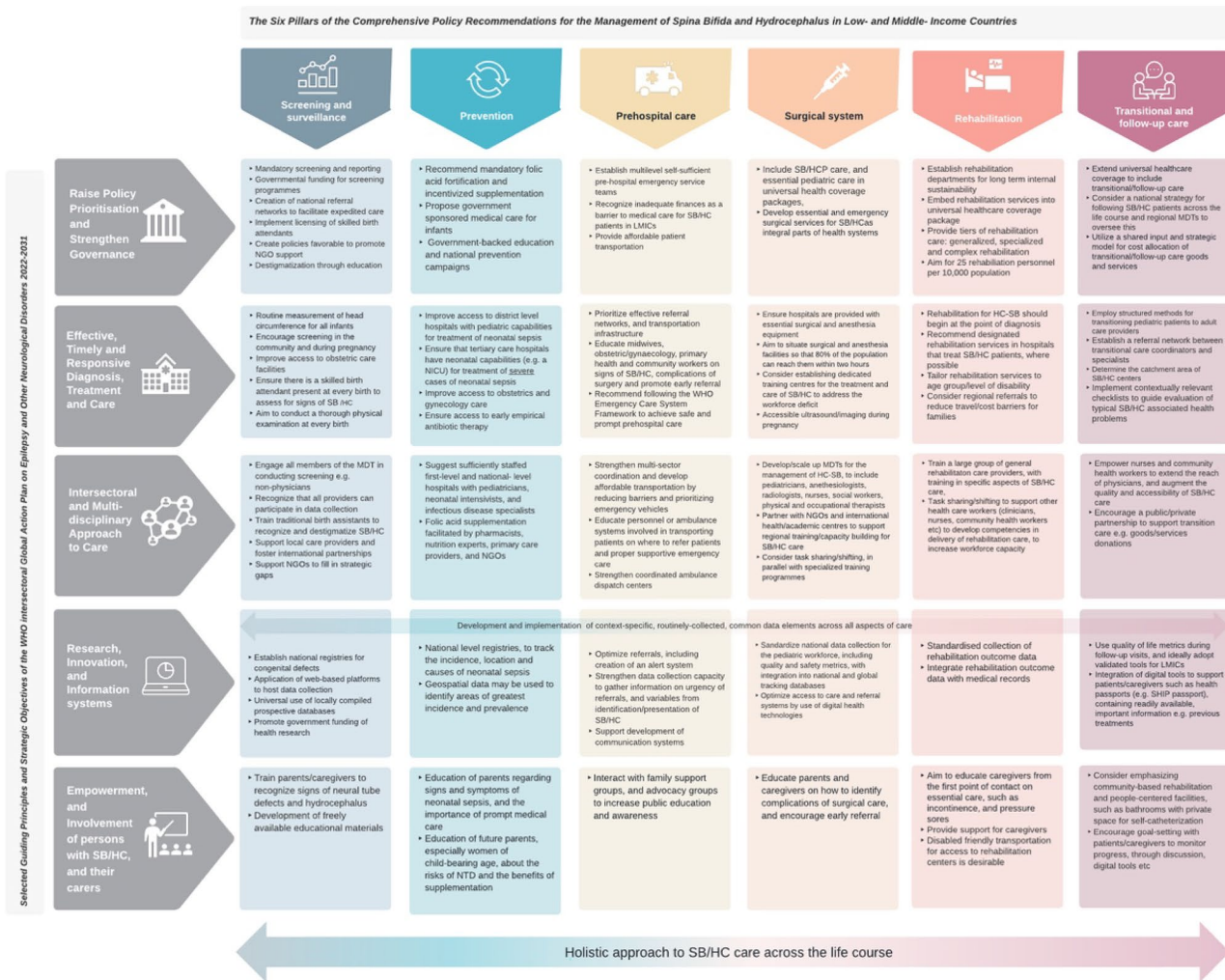


Fig. 1 Matrix of selected CHYSR policy recommendations and strategic objectives of the WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders 2022–2031 (IGAP). SB, spina bifida; HC, hydrocephalus

- These efforts recognize the role of research and data in improving neurological/neurosurgical care. Neurosurgeons can establish or lead research groups of local trainees, medical students, and other healthcare professionals to conduct SB studies. CHYSR recommends governments build SB care into their national health strategies (possibly working with NGOs), to improve access, education, and prevention efforts. IGAP recommends to strengthen the public health approach to epilepsy and to promote synergies with other neurological disorders.
- Finally, both CHYSR and IGAP address development of neurosurgical and neurological care through the entire care pathway, from prevention and surveillance to treatment and rehabilitation, and continual transition from birth to adulthood. It is important that neurosurgeons participate in the entire care spectrum and consider improvements holistically. A key component of

the CHYSR/IGAP effort is to foster research, develop innovation strategies, and strengthen information systems for SB/epilepsy and other neurological disorders (Fig. 1).

Folic acid fortification

Although data are available for 30 years regarding FA fortification, many regions of the world have not yet benefited from this simple dietary adjustment or policy modifications. Much like iodine fortification is now accepted globally, we have an opportunity to implement a very positive change that will likely affect 300,000 newborns annually worldwide [1, 5, 8, 10]. This is quite similar to the global polio epidemic several decades earlier, and a recent World Health Assembly initiative is underway.

The implementation of FA fortification is a mixed conundrum of issues with political and financial concerns. The

dietary preferences globally and the methods of obtaining basic food staples are vastly different in various regions of the world. In some areas, practice of flour grinding is done either at home or in the villages locally, and is highly unlikely that fortification processes will affect them. However, in many places, fortification has been achieved with great success with reasonably low financial resources. Similarly, rice and corn flour fortification efforts are underway, and recently, FA in salt is being considered.

Maternal FA concentrations increase in a dose response manner with increased consumption of fortified foods. There are ample data to show that such a change would drastically reduce the incidence of SB and anencephaly [5, 50]. Current efforts at FA fortification should be a multi prong approach, and research has supported the usefulness and efficacy of FA fortification and LMICs. A tremendous return on investment (approximately 18:1) has been documented, with hopes of increased efficiency in the future [7, 12].

Globally, joint effort by medical personnel and politicians, with participation from the fortification teams, is needed (such as millers and distributors). Effective communication and supply chain management facilitates this process with a highly successful integration. In many areas, resource limitation, lack of knowledge or communication, and in some cases political interference have caused a significant delay in achieving this investment in public welfare.

Financing

Financial constraints often pose a barrier for SB patients, and some options may be considered by LMIC governments to help with such issues. They may consider embedding pediatric neurosurgery into a universal health coverage package, provide affordable transportation, or offer easier access to medical care (i.e. telemedicine visits). Encouraging public–private–partnerships (PPPs) or utilizing a shared strategic model for cost allocation of goods and services may also benefit SB patients.

Governments sometimes need reminders of the financial burden and options of a successful SB prevention strategy to reduce significant expenses. However, data are lacking regarding true global incidence, and therefore, the potential benefit of FA fortification is sometimes difficult to demonstrate to the political powers. In some countries, fortification efforts are considered expensive and relatively ineffective — such misconceptions need to be rectified with sound scientific data and educational campaigns towards this goal.

Support from NGOs can fill in strategic gaps, and international partnerships may support training or capacity building for SB care. Prevention strategies will reduce long-term expenditure, allowing government funding for local research and improved outcomes.

Conclusion

Certainly, many challenges lie ahead for LMICs, including inadequate information, resources, conflicting lobbying efforts, and incomplete understanding of the burden on the healthcare system. The commitment to invest in comprehensive SB management (as proposed by CHYSPR and IGAP), including prevention and prehospital care, will no doubt save many lives and reduce much pain and disability worldwide.

We encourage support to improve SB patient care and request governments to adopt recommendations that reduce premature mortality due to non-communicable diseases. Spina bifida prevention by folic acid fortification is paramount, and neurosurgeons are encouraged to support such initiatives globally.

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Availability of data and materials Not applicable.

Declarations

Ethical approval Not Applicable.

Conflict of interest None.

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