

Global Health

Spina Bifida Global Learning Collaborative: Educating the next generation of clinicians, researchers, and advocates

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Abstract.

PURPOSE: This project aimed to launch an international learning community to guide the development of a spina bifida (SB) curriculum for global health trainees.

METHODS: Using a descriptive study design, a convenience sample of SB curricula were identified in 2022–23 by members of the Spina Bifida World Congress Outreach Committee and evaluated during a series of monthly Zoom calls to discuss SB education in a global health context. Participants included (1) leadership from the ReachAnother Foundation, (2) invited panelists from the Spina Bifida World Congress Global Health Symposium, and (3) global health students and preceptors. Education initiatives in Ethiopia, Sweden, Argentina, Ecuador, and the United States were evaluated vis-à-vis format and content.

RESULTS: All of the education initiatives referenced the framework of the World Health Organization International Classification of Functioning, Disability and Health. Formats varied and included both virtual and interactive workshops, print materials, videos, and guides for small group discussion. Content addressed four domains: Folate Prevention, Neurosurgical Training, After Care, and Data Collection. A multidisciplinary approach, partnerships with families, and workforce pipeline

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training were identified as guiding themes for educating the next generation of SB researchers and clinicians in global health settings.

CONCLUSION: The Spina Bifida Global Learning Collaborative is a transnational group of advocates, clinicians, and investigators whose mission is the advancement of SB-related global health education. Lessons learned from the collaborative are being leveraged to develop a global health curriculum for learners, which may improve services for individuals with SB around the globe.

Keywords: Spina bifida, global health, interprofessional education

1. Introduction

The global health symposium at the 2023 Spina Bifida World Congress (SBWC) provided inspiration for what can be accomplished when global health [1–5] principles such as collaboration, advocacy, and political will are linked with biomedical research and clinical care [6]. For example, advocacy by the Global Alliance for the Prevention of Spina Bifida resulted in the passage in May 2023 of a resolution by the World Health Assembly to accelerate food micronutrient fortification worldwide [7–9]. The symposium also made evident that much work remains. Equitable access to prenatal surgery and coordinated follow-up care remain elusive goals, both within high-income nations such as the United States (among disadvantaged subgroups) [10], and in low-resource settings around the world [11, 12]. Global migration trends threaten to further magnify disparities in the coming years [13].

Proactive efforts are needed to train the next generation of professionals to provide care within a global health framework. The spina bifida (SB) research and advocacy community is uniquely positioned to lead the way. This is because health outcomes for people with SB are dependent upon the *integration* of cutting-edge advances in biomedical care with community support across the lifespan. Just as disparities in SB outcomes are dramatically exposed when biomedical advances are introduced in isolation, so too can health equity be achieved and celebrated when dedicated attention is focused on the *integration* of cutting-edge technologies with a community-centered approach to follow-up care.

The 2023 SBWC's Global Health Symposium was leveraged as the official launch of the Spina Bifida Global Learning Collaborative, a transnational, multi-disciplinary group of advocates, clinicians, and investigators dedicated to SB-related global health education among professional trainees. The collaborative conducts monthly meetings by Zoom to

develop educational materials and welcomes international participation:

Spina Bifida Global Learning Collaborative Interest Form: <https://forms.gle/j7xwkMz51LaGL2rR6>.

2. Methods

This is a descriptive study of a convenience sample of SB curricula that were identified in 2022–23 by members of the SBWC Outreach Committee. The Committee conducted a series of monthly Zoom calls to discuss SB education in a global health context using a “community case conference” format. Participants included (1) leadership from the ReachAnother Foundation (RAF), (2) invited panelists of the SBWC Global Health Symposium, and (3) global health students and preceptors. In addition to the case presentations, the group also shared information about global health curricula [Box 1] and resources relevant to SB care in the global health setting [Box 2]. The activities and resources were presented orally and in poster format to facilitate collaboration with symposium attendees.

3. Results

Five SB-related global health programs that exemplified the values of the Spina Bifida Global Learning Collaborative were identified.

3.1. Ethiopia: RAF

In Ethiopia, Centers of Excellence in Pediatric Neurosurgery support Ethiopian children and families affected by neural tube disorders by developing programs in four main areas: Prevention, Treatment, Aftercare, and Data Collection/Evidence Generation. This is accomplished with the support of the RAF, a non-governmental organization (NGO) that

Box 1. Selected Open-Source Global Health Training Resources

Consortium of Universities for Global Health educational modules:

<http://www.cugh.org/resources/educational-modules>

Global Health in Pediatric Education: An Implementation Guide for Program Directors:

<https://www.abp.org/ghpdguidehome>

Consortium of Universities for Global Health Education Competencies Tool-Kit:

<https://www.cugh.org/wp-content/uploads/sites/95/2020/05/CUGH-Global-Health-Toolkit-Web-Version.pdf>

American Academy of Pediatrics, Immigrant Child Health Toolkit:

<https://www.aap.org/en/patient-care/immigrant-child-health/>

Global Initiative for Children’s Surgery: <http://www.globalchildrensurgery.org/>

Training guide for implementation of the UN Convention on the Rights of Persons with Disabilities:

https://www.ohchr.org/Documents/Publications/CRPD_TrainingGuide_PTS19_EN%20Accessible.pdf

International Organization for Migration World Migration Interactive Educators’ Toolkit:

<https://wmr-educatorstoolkit.iom.int/>

Ubuntu Hub - International Centre for Evidence in Disability, London School of Hygiene and Tropical Medicine:

<https://www.ubuntu-hub.org>

Global Alliance of Assistive Technology Organizations: <https://www.gaato.org/>

WHO 2023 guidelines on the provision of manual wheelchairs in less resourced settings:

<https://www.who.int/publications/i/item/9789240074521>

is a change champion for SB care in Ethiopia [14]. The RAF, in collaboration with Ethiopian and international partners, developed a handbook and instructional videos for families as well as a three-day long “train the trainer” curriculum for medical professionals. A basic tenet of the RAF approach to professional training is a focus on “what parents can do” to support their child in daily activities. RAF partnerships and training materials are listed in Box 3.

3.2. Sweden: Disability Day

The goal of Lund University’s “Disability Day” for public health students is to increase awareness of disability in terms of lived experience. Morning lectures are presented by a mix of providers, researchers, students, and people with disabilities. In the afternoon, students break into discussion groups and then reconvene to share insights with the entire class. Participants represent diverse nationalities and include nurses, dentists, physical therapists, pharmacists, and physicians, as well as students from non-health-related fields. As a direct outcome of “Disability Day,” several students have decided to focus their thesis work on SB within global health settings. “Disability Day” will be replicated in Helsinki, Finland, with physical therapy, occupational therapy and social work students.

3.3. Sweden: Cognitive Orientation to Daily Occupational Performance (CO-OP) training

In Western Sweden, a family-centered approach [15] and active participation of the child in medical visits is standard of care, in alignment with the United Nation’s Convention on the Rights of the Child [16] and the Swedish Patient Act [17]. Health care encounters focus on activity and participation, and interventions are guided by what the individual desires to improve [18]. The CO-OP is a generic, performance-based, and person-centered approach that engages the individual at a metacognitive level to enable them to solve performance problems on their own as life unfolds [19, 20]. The CO-OP approach does not require any specific equipment and can be implemented in low-resource settings. A two-day professional training in the CO-OP approach is available online [Box 2].

3.4. Argentina: Argentine Assistive Technology Association

The Argentine Assistive Technology Association conducts family-centered trainings among indigenous communities in order to promote independence and compensate for functional limitations such as

Box 2. Selected Resources for Spina Bifida Care in Global Health Settings

Spina Bifida Association Guidelines for the Care of People with Spina Bifida (Journal of Pediatric Rehabilitation Medicine, Volume 13, Issue 4, 1 Jan. 2020):

<https://content.iospress.com/journals/journal-of-pediatric-rehabilitation-medicine/13/4>

Spina Bifida Association Spanish language materials:

https://www.spinabifidaassociation.org/resource/?audience=en-espanol&topic=&post_tag=

Spina Bifida Association Lifespan Bowel Management Protocol:

<https://www.spinabifidaassociation.org/lifespan-bowel-management-protocol/>

Spina Bifida Association level of lesion infographic:

<https://depts.washington.edu/dbpeds/HOW%20SB%20LESIONS%20IMPACT%20DAILY%20FUNCTION.pdf>

International Federation for Spina Bifida and Hydrocephalus Grand Rounds for Clinicians:

<https://www.ifglobal.org/our-work/if-conferences/>

International Federation for Spina Bifida and Hydrocephalus advocacy toolkit:

<https://www.ifglobal.org/publications/if-toolkit-steps-for-an-advocacy-campaign/>

International Federation for Spina Bifida and Hydrocephalus transnational twinning between national organizations of persons with disabilities:

<https://www.ifglobal.org/events/cosp16-side-event-reaching-out-together/>

Cognitive Orientation to daily Occupational Performance (CO-OP) approach: <https://icancoop.org/>

PUSH! Report Cards on spina bifida prevention: <http://www.pu-sh.org/global-report-cards>

PUSH! Campaign aims to create a vast community for information sharing: <http://www.pu-sh.org/campaigns>

CURE NeuroDatabase and protocol: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7042585/>

Building Local/Global Spina Bifida Communities with Adaptive Design:

https://www.upstate.edu/specialneeds/pdf/inclusive/2018_building-local-global-spina-bifida-communities-with-adaptive-design.pdf

Construyendo Comunidades Locales/Globales de Espina Bifida con Diseño Adaptado:

https://www.upstate.edu/specialneeds/pdf/inclusive/2018_construyendo-comunidades-locales-globales-de-espina-bifida-con-diseno-adaptadotagged.pdf

mobility, communication, self-care, and cognition [21]. It is a member of the Global Alliance of Assistive Technology Organizations (GAATO), a non-profit association committed to equitable and reliable access to assistive technology (AT) using an “open systems” approach that encompasses task-shifting in skill-mix systems, remote support for community-based providers, peer support networks, and the involvement of AT users themselves [22]. GAATO recognizes five interlinked areas as “strategic drivers” for global access to AT: people, policy, products, service provision, and personnel [23].

3.5. Syracuse, USA/Ibarra, Ecuador:

Local/global adaptive design

In the summer of 2018, adolescents with SB from Syracuse, New York, participated in a

six-week “Local/Global Adaptive Design” camp. At the same time, in Ibarra, Ecuador, children with SB and their families gathered weekly at Prótesis Imbabura, a prosthetics, orthotics, and adaptive design center, to build adaptive designs using cardboard and other low-cost materials. Pediatric residents, public health students, and designers also participated in the project. The focus was on bi-directional learning [5] as both groups shared design ideas via video conference and social media. This pilot project has evolved into an annual interdisciplinary global health experience in Ibarra, Ecuador (for manual, see Box 2); a partnership with Loop, a company that makes cushions from recycled bicycle inner tubes; and a platform to crowdsource design ideas for mobility, continence, skin health, and cognition.

Box 3: ReachAnother Foundation Partnerships and Training Materials**Partnerships:**

HOPE SBH, parent support group for aftercare in Ethiopia: <https://hope-sbh.org/>

University of Gondar Physiotherapy Department, Ethiopia:

<https://uog.edu.et/academic-units/college-of-medicine/department-of-physiotherapy/>

Pediatric Neurosurgery at Children's of Alabama and the University of Alabama at Birmingham:

<https://www.childrensal.org/services/neurosurgery>

Center for Spina Bifida Prevention, Emory University Rollins School of Public Health:

<https://prevents-pinabifida.org/>

Lurie Children's Pediatric Neurosurgery, Chicago, Illinois:

<https://www.luriechildrens.org/en/specialties-conditions/pediatric-neurosurgery/>

Illinois Spina Bifida Association: <https://i-sba.org>

REDCap database: <https://www.project-redcap.org>

International Federation for Spina Bifida and Hydrocephalus: <https://www.ifglobal.org>

NeuroKids: <https://neurokids.org>

Child-Help International: <https://www.child-help.international/projects/ethiopia>

Global Alliance for Prevention of Spina Bifida F (GAPSBiF):

<https://www.theg4alliance.org/gapsbif#:~:text=A%20coalition%20of%20individuals%20and,of%20spinal%20dysraphism%20in%20children>

G4 Alliance for Surgical, Obstetric, Trauma and Anaesthesia Care: <https://www.theg4alliance.org>

Training materials:

ReachAnother Foundation: <https://reachanother.org/>; <https://www.reachanother.nl/>

ReachAnother Foundation films on Vimeo: <https://vimeo.com/channels/982712/videos>

ReachAnother Foundation Physiotherapy training film for babies with spina bifida and hydrocephalus:

<https://vimeo.com/513303189>

ReachAnother Foundation Instruction video for parents: What parents can do:

<https://www.youtube.com/watch?v=pgAFYEEbYM>

4. Conclusions*4.1. Innovation through a learning collaborative*

Interest in global health as an academic discipline has increased in the last decade [24]. Most US medical schools and many pediatric residency programs are actively incorporating global health principles and social determinants of health into curriculum redesign [25]. To the authors' knowledge, this is the first transnational learning community specifically convened to address the need for training around SB care in a global context.

4.2. Lessons learned

True Multidisciplinary Collaboration:

A key tenet of SB care is the multidisciplinary approach [26]. Members of the learning collaborative, representing numerous disciplines and geographical locations of impact, embraced a broad approach to the recruitment and inclusion of participants to assure a multidimensional content to the proposed curriculum.

Community-centered Agenda:

The learning collaborative recognized the importance of including people with SB and their care partners in shaping organizational priorities [27]. The appreciation of this crucial, yet often overlooked, concept will shape the curriculum, for unless learners are explicitly taught its importance, they are likely to ignore its application in their future careers.

Workforce pipeline strategy:

Not only in low-income countries, but also in pockets of the populace in wealthier nations, individ-

uals live with chronic non-communicable conditions yet lack appropriate levels of care [11]. To mitigate the effects of chronically under-resourced medical provision, governments and educational institutions can strategically invest in scaffolding medical systems by reinforcing training programs to augment the workforce. The professionals who make up the Spina Bifida Global Learning Collaborative are already practitioners and their energies could be invested elsewhere; however, a core pillar of the global learning collaborative is not only to develop a curriculum for learners but also to foster mentorship of the next generation of professionals. Of note, collaboration and outreach with global health training initiatives has the potential to bring a talented pool of students into the SB research community.

5. Conclusion

Global health places a priority on improving health and achieving equity in health for all people worldwide. There is a clear need for efforts to train the next generation of professionals to provide SB care with a social justice lens and in a global health framework. A transnational learning community of advocates, clinicians, and investigators was formed to advance SB-related global health education. The five SB-related global health initiatives presented at the SBWC and some of the lessons learned from these programs may prove valuable to other educators. These lessons are informing the development of a formal global health curriculum, which will hopefully ultimately support the improvement of services for individuals living with SB in many regions of the globe. The plan is to develop, pilot, and formally evaluate a SB curriculum for global health students in the coming years. Working together as a global learning collaborative will also provide insights into effective and equitable integration of highly technical specialized care with community-based supports and services for children with spina bifida.

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Conflicts of interest

The authors have no conflicts of interest to disclose.

Ethical considerations

This report describes global health education initiatives and is exempt from Institutional Review Board approval.

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