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**International Care**

## Folic acid prescription practice for high-risk prevention of spina bifida at a tertiary care hospital in Addis Ababa, Ethiopia

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**Background:** The current guidance promotes supplementation of therapeutic-dose folic acid (4-5 mg/day pills) for high-risk pregnancies to prevent spina bifida recurrence. There is a high prevalence of spina bifida in Ethiopia. We examined the 5 mg/day folic acid prescription pattern for high-risk mothers whose babies receive spina bifida surgery in a large urban tertiary hospital in Ethiopia.

**Methods:** Data were extracted from an electronic database maintained by a large urban tertiary care hospital that provides care for babies with spina bifida in Ethiopia. An eligible baby-mother pair comprised of mothers and their babies with either “myelomeningocele” or “meningocele” diagnosis, and with at least one patient encounter logged in the hospital database. Cases were born between January 2019 and June 2022. At each patient encounter, a trained study coordinator recorded whether the mother received a 5 mg/day folic acid prescription. We conducted a descriptive analysis examining the pattern of folic acid for spina bifida recurrence prevention.

**Results:** There were 500 baby-mother pairs examined, 340 (68%) received a prescription for 5 mg/day folic acid pills for 120 days (sufficient for about four months). Of the 340 mothers, 331 (97%) received their folic acid prescription at their baby’s first or second patient encounter at the hospital. Majority of mothers (94%) had a documentation of only one prescription (i.e., 120 tablets) for the study duration. The percent of mothers that received folic acid prescriptions at least once varied by the baby’s year of birth (2019: 75%; 2020: 92%; 2021: 46%; Jan 2022 – Jun 2022: 79%).

**Conclusions:** Our study highlights the implementation of spina bifida recurrence prevention guidance in a developing country scenario where only a proportion of cases receive spina bifida surgery; additional efforts must be made to reach all mothers with a history of pregnancy affected by spina bifida.

## Crann Centre - Indiana University Riley Children’s Health: A binational academic-community partnership to improve care for persons with spina bifida and other neuro-physical disabilities

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**Background:** In 2017 Riley Children’s Health/Indiana University School of Medicine (Indianapolis, Indiana USA) and Crann Centre (Cork, Ireland) launched an academic-community partnership to survey opportunities to improve the quality of life for people with spina bifida and other neuro-physical disabilities, as a binational collaboration. The goal was formed to promote achievement of best life through a comprehensive, whole family model including health, independent living and economic stability, education and employment, and social supports and networks, based on the Aspen Ascend 2-Gen approach.

**Methods:** Through bidirectional visits, team members from both institutions explored service delivery and opportunities in each other’s location. Team members visited with primary and specialty care facilities, community and governmental organizations, as well as families and self-advocates. Regular virtual meetings were hosted between the two organizations. Programming and piloting of new processes were trialed and developed.

**Results:** Opportunities and challenges experienced by families in both countries had marked similarities.

There are notable specific differences in types of government services, however opportunities to build on improvements were defined. Over the subsequent five years, the collaboration has yielded occupation therapy programming in wheelchair skills training which address both confidence and community participation and development of processes for health education and care coordination.

**Conclusions:** Binational academic-community partnerships can work together to enhance programmatic creativity and a holistic view of family needs and services for individuals with spina bifida and neurophysical disabilities.

### Addressing social determinants of health through electronic medical record customization: The use of quality improvement, telemedicine and care coordination to serve immigrant families

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**Background:** Globally, the number of immigrants and refugees is escalating. While immigration is often a result of social determinants of health (SDOH) including poverty, war-associated violence, political discrimination, and work-related prospects, immigration itself can be conceptualized as a SDOH. Concomitantly, there is substantial global variation in neural tube defects (NTDs) prevalence rates. In certain regions of Latin America, it is as high as 96 cases per 10,000. Even as Latinos immigrate into the US, they consistently have a higher birth prevalence of NTDs. Given the occurrence of adverse SDOH among patients, many of whom are Latino, we aimed to customize our electronic medical record (EMR) to track and address SDOH.

**Methods:** Utilizing quality improvement methodology, we catalyzed care coordination and supported the National Spina Bifida Patient Registry (NSBPR) activities at our institution by developing a platform for a structured data entry system (SDES). Starting in September, 2020, the four fundamental steps were to (1) facilitate an advisory committee to safeguard the standard clinical protocols, (2) characterize barriers to implementation, (3) evaluate workflow to

sustain data entry capture, and (4) manage the technology platform for seamless integration.

**Results:** The EMR was leveraged through the systematic use of a SDES, which allowed data entry based on predefined categories and conditions. The SDES permitted standardization of registry data entry and collection, allowed easier reporting back of the discrete data and more efficient cross care coordination and telemedicine appointments. Additionally, during *safety huddle* meetings and through care coordination efforts the use of a EMR visual *SDOH wheel* was useful in addressing adverse social determinants (e.g. food insecurity concerns, transportation needs, immigration related requirements, etc.).

**Conclusions:** We discuss lessons learned in the service of immigrant and asylum seeking families. The presented framework can assist in the care and advocacy of displaced populations both in the US and abroad.

### The unique experience of caring for spina bifida patients in Doha, Qatar

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**Background:** Although spina bifida is the second most common form of childhood motor disability, global prevalence is quite variable. Qatar's prevalence rate of 10.9 per 10,000 births is lower than some other countries in the Middle Eastern region, such as Iran at 82.9 per 10,000 births. However, this may be partially related to the large expatriate population in Qatar and other Gulf Cooperation Council (GCC) countries. Qatar expanded its internal pediatric hospital network which has created unique experiences in the care and management of conditions such as Spina Bifida.

**Methods:** The first multidisciplinary clinic in Doha, Qatar started at Hamad Hospital in 2010. In 2018, the multi-disciplinary clinic was transferred to Sidra Medicine. Various specialists and consultants participated in the care of spina bifida patients. Collaborations continued with Hamad hospital for equipment, orthotic needs, and a transition program. **Results:** The number of spina bifida patients expanded from 80-90 patients to at least 120 patients

after the transition to Sidra Medicine. The multidisciplinary clinic provided access to an expanded number of pediatric specialists. There were various barriers to care in relation to access to services and school; equipment and supplies; clinic space and staffing; and community programs. The large expatriate population along with local customs and culture influenced healthcare practices. Despite some barriers, other spina bifida team goals were accomplished.

**Conclusions:** The multidisciplinary spina bifida clinic established in Doha, Qatar accentuates diverse healthcare practice patterns in an international setting.

### Local/global information sharing of assistive technology solutions developed by people with spina bifida

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**Background:** One of the ten recommendations made by the World Health Organization's Global Report on Assistive Technologies (AT), issued in May 2022, is to actively involve users of AT and their families in design, monitoring and evaluation, repair and maintenance, and peer to peer training related to AT. Regional spina bifida centers can serve as a hub for collecting and disseminating community-based AT solutions.

**Methods:** We applied principles of community based participatory research. Starting with our own regional spina bifida center in Syracuse, New York, we systematically asked patients and families to share their design solutions for (a) mobility (c) continence (d) skin health, and (e) enabling environments. Our interview template also elicits ideas for improving access to AT in our community, focusing specifically on the patient experience with AT products, provision, personnel and policy.

**Results:** AT innovations developed by patients and families at our regional spina bifida center are entered into a searchable visual archive that can be queried by AT category as well as by location, in the form of a "community snapshot" of design innovation. Our digital platform is open access and can be used by spina bifida centers in other regions of the world.

**Conclusions:** We plan to link our digital platform for information sharing of AT innovation with a toolkit on community centered spina bifida care for people with spina bifida and their families, global health students, design students, clinicians, and community-health workers. The long-term goal is better integration of AT products, innovation, and service provision with medical care at regional spina bifida centers. This is in alignment with the WHO guidance that AT users with their families and communities, must be placed at the core of everything that is being done to ensure AT provision, use and impact measurement.

### Counseling families regarding international adoption of children with spina bifida

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**Background:** International adoption brings thousands of children to the United States every year. Congenital anomalies are overrepresented in this population, and adoptees may require complex medical care upon arrival. Preparation of the adoptive family is critical for a successful adoption. The objective of this project is to assess the experience of parents who care for adopted children with spina bifida.

**Methods:** Families of internationally adopted children with spina bifida (SB) were surveyed. Using a graded scale, they were asked to evaluate how well their experiences post adoption aligned with their expectations and education they received pre-adoption. Variables included bowel and bladder management, surgical management, and social skills. Open comments were then collected regarding the advice they would offer to other families in their situation.

**Results:** We identified 49 families with internationally adopted children who are or were followed in our SB clinic. Twenty-five families responded to our survey (51%). Most children had occult forms of dysraphism (80%). Forty percent reported seeking consultation in the International Adoption Clinic prior to adoption and thirty-six percent reported reaching out to a pediatric neurosurgeon. Families reported this to be valuable. Thirty-six percent

reported reaching out to a pediatric neurosurgeon and reported this to be valuable. On average, parents' expectations of the clinical outcomes for their child met their expectations. Bowel and bladder function was reported to be better than expected. Surgical complications were the most common unanticipated difficulty.

**Conclusions:** Preparation of adoptive families contributes to the well-being of the family and the child.

Meeting with an international adoption clinic and/or pediatric neurosurgeon to review care for a child with SB prior to final decision can be a useful part of preparation. Feedback obtained from families of adoptive children with spina bifida will help providers better understand how to prepare and reach future adoptive families.