

Editorial

From prenatal care to spina bifida related mortality: The lifespan is marked by transitions experienced by increasing immigrant and international populations

Jonathan Castillo^{a,b,*}, Judy K. Thibadeau^c, Tim Brei^{c,d} and Heidi Castillo^{a,b}

^a*Developmental Medicine, Department of Pediatrics, Children's Nebraska Hospital/ University of Nebraska Medical Center, Omaha, NE, USA*

^b*Fetal Center, Department of Obstetrics and Gynecology, Baylor College of Medicine, Houston, TX, USA*

^c*Spina Bifida Association, Arlington, VA, USA*

^d*Division of Developmental Medicine, Department of Pediatrics, Seattle Children's Hospital and the University of Washington School of Medicine, Seattle, WA, USA*

Abstract. Whether it is for collaboration on folic acid fortification or the standardization of care efforts concerning neurogenic bowel dysfunction, a global forum on neural tube defects related issues is needed. Propitiously, the 2023 Spina Bifida World Congress sponsored by the Spina Bifida Association (SBA) was a catalyst for transnational dialog in the field of spina bifida (SB) research. Concurrently, the *Journal of Pediatric Rehabilitation Medicine* (JPRM) provides a platform for both international research as well as numerous clinical and educational projects, such as *The Lifespan Bowel Management Protocol*, and social interventions taught through the American Academy of Pediatrics' *Spina Bifida Transition ECHO*. Through this *open access* issue, work by colleagues in Ethiopia, the Nordic countries, and Switzerland, as well as among other transnational populations is highlighted. The development of the *Spina Bifida Global Learning Collaborative* is also showcased, representing a training initiative across four continents. Correspondingly in this issue, *JPRM* published an update to the Transition Guidelines for the Care of People with Spina Bifida. The clinical guidelines are a product of the SBA Collaborative Care Network cooperative agreement with the National Center on Birth Defects and Developmental Disabilities in the Centers for Disease Control and Prevention. While colleagues across the globe remain committed to native, immigrant, and displaced populations of individuals affected by SB, *JPRM* will continue to distribute premier research in multidisciplinary care, education, and advocacy.

Keywords: Myelomeningocele, Transition, guidelines, Global Health, International Collaboration

Fortification with folic acid periconceptionally has been documented to decrease the prevalence of neural tube defects (NTDs) by nearly 70%, and up to half of all NTDs are routinely prevented by fortification

[1, 2]. Therefore, fortification of staple foods such as wheat, rice, and corn is required to meaningfully improve maternal folic acid levels, leading to NTD prevention. However, addressing this burden of disease in low- and middle-income countries requires dynamic collaborative efforts between medical professionals and local policymakers [3]. On the other

*Corresponding author: Jonathan Castillo, Developmental and Behavioral Pediatrics, 8200 Dodge Street, Omaha, NE 68114, USA. E-mail: joncastillo@childrensnebraska.org.

hand, 80% of individuals living with spina bifida (SB) are affected by neurogenic bowel dysfunction (NBD). Nevertheless, because of the significant variability among medical or surgical specialties routinely managing NBD, performing and disseminating research on NBD is difficult [4].

Therefore, whether it is for the needed collaboration on folic acid fortification or the standardization of care and research efforts concerning NBD, a global forum for professionals working on SB-related issues is critically needed. Propitiously, the 2023 Spina Bifida World Congress sponsored by the Spina Bifida Association (SBA) was a timely catalyst for the transnational dialog and efforts in the field of NTD research [5]. As the only international conference dedicated solely to comprehensive SB research, it showcased the landscape of investigation and addressed current gaps and opportunities in SB care. Concurrently the *Journal of Pediatric Rehabilitation Medicine* (JPRM) has emerged as a leader in publishing innovations in this area of multi-disciplinary education and research.

Now in its seventh special issue on SB care and research, JPRM provides a platform for both international research as well as numerous clinically and educationally relevant projects, such as *The Lifespan Bowel Management Protocol*, and social interventions taught through the American Academy of Pediatrics' *Spina Bifida Transition ECHO* [6]. This special issue also highlights work by international colleagues in Ethiopia, the Nordic countries, and Switzerland, as well as among other transnational populations. Through this *open access* issue, not only are these educational and research efforts showcased, but also the development of the *Spina Bifida Global Learning Collaborative*, representing a training initiative across four continents. Indeed, it is a stimulating time to learn from colleagues across the globe about culturally appropriate innovations through thoughtful literary discussion.

As with previous issues, JPRM remains committed to publishing updates to the "Guidelines for the Care of People with Spina Bifida." These guidelines are a product of the SBA Collaborative Care Network cooperative agreement with the National Center on Birth Defects and Developmental Disabilities in the Centers for Disease Control and Prevention [7]. It is exhilarating to see how these guidelines are continually improved by active investigative efforts and through which methods these are implemented and evaluated in centers across the world.

In this issue also, a new generation of clinicians, who are ushering in a dawning technological era to both serve and study SB, are sculpting innovative concepts such as "smart socks" and "customization of electronic medical records" to improve the lives of vulnerable and immigrant families. Reports such as these are highlighted and can serve others to continually adapt and bring about immediate improvements in health care delivery in diverse settings.

Lastly, it is worth noting that this issue spans many domains of SB care including bowel management, transition, mortality, physical activity, fetal surgery follow-up, and neurosurgical manifestations. These publications represent the breadth and scope of SB care and the diversity of learners and researchers alike. While colleagues across the globe remain committed to native, immigrant, and displaced populations of individuals affected by SB, JPRM will continue to distribute premier research in the multidisciplinary care, education, and advocacy around SB – both through this issue and well into the future.

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