

Editorial

Guidelines and scientifically-based spina bifida care: Guidance across the lifespan in a global health context

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Abstract. The COVID-19 pandemic has reminded us that, if of nothing else, we live in a globalized community. Enthusiasm for evidenced-based medical knowledge is also contagious. Just as the incidence of SARS-CoV-2, the associated coronavirus, has had a borderless impact on global public health, so too neural tube defects have widespread significance. Previously, the concept of “blue marble health” was introduced as a policy framework to illustrate trends in the geographic distribution of health disparities affecting at-risk populations that live, not only in low-income countries, but also in pockets of the populace in wealthier nations. Subsequently, the Spina Bifida Association's Collaborative Care Network, through a cooperative agreement with the Centers for Disease Control and Prevention, recently produced the “Guidelines for the Care of People with Spina Bifida.” While language differences, immigration, cultural beliefs, acculturation, local resources and social determinants of health, must be taken into account when these guidelines are implemented across the globe, they could not come at a more suitable time. The current digital age, as well as open access to this special issue, will ensure their ongoing wide distribution.

Keywords: Guidelines, myelomeningocele, social determinants of health, blue marble health, immigration, global health, spina bifida

The COVID-19 pandemic has reminded us that, if of nothing else, we live in a globalized community. Enthusiasm for medical knowledge, in as much as it can be easily shared across borders, is also contagious. Just as the incidence of SARS-CoV-2, the associated coronavirus, has had a borderless impact on global public health, so too neural tube defects (NTDs) have widespread significance [1]. Globally, nearly 300,000 babies are born with NTDs each year [2]. Broadly shared scientific guidance regarding the folic acid for-

tification of staple foods has made a positive impact on global NTD prevalence, albeit with divergent implementation rates among many countries [3]. These international gains are due to clinical recommendations for folic acid fortification made widely available, as well as to the education and advocacy of professionals around the world who leveraged medical knowledge to craft policies to benefit broad sectors of their countries' population [4]. Just as the global medical community has rallied around national fortification efforts, in the midst of this borderless pandemic there is also reason for optimism for gains in the transmission of medical knowledge. Increasingly, our digital age is bringing together healthcare providers and investigators to share what they are learning with colleagues around the world.

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An example of this spirit is embodied in the development and dissemination of the new clinical care guidelines for people living with spina bifida. The Spina Bifida Association's (SBA) Collaborative Care Network, through a cooperative agreement with the National Center on Birth Defects and Developmental Disabilities (NCBDDD) in the Centers for Disease Control and Prevention (CDC), recently updated the care guidelines. To accomplish this, the SBA convened international, multidisciplinary teams of clinical and research experts as working groups [5]. Utilizing the International Classification of Functioning, Disability and Health (ICF) model as a framework, a systematic review of multiple databases was completed as the foundation towards consensus building [7]. This approach led to production of the fourth edition of the "Guidelines for the Care of People with Spina Bifida." This effort, involving over 100 international experts, employed evidenced based-research and consensus methodologies to produce a comprehensive set of guidelines covering topics from prenatal counseling to transitions and aging [5]. These guidelines know no borders and can be used for care in a broad array of locations across the globe.

The concept of "blue marble health" was introduced in 2013 as a policy framework to illustrate trends in the geographic distribution of neglected tropical diseases affecting at-risk populations that live not only in low-income countries but also in pockets of the populace in wealthier nations [8]. It is a new global health paradigm that challenges a traditional approach that simply juxtaposed health outcomes in low-income versus high-income countries. "Blue marble health" explains the varied prevalence and related needs of SB care among developed economies such as many in North America and Europe [9]. Despite the fact that fortification recommendations athwart the globe, recalcitrant rates of new folic acid preventable NTD cases remain high in many nations [3]. Additionally, even among those with robust services for children, many countries struggle to provide adequate services for adults with SB. This challenge is magnified in low-income countries and among immigrant or minority populations in wealthier nations. Therefore, global accessibility to the guidelines is vital, as healthcare professionals embedded in local communities will seek to use this guidance to provide high-quality care.

In our "blue marble world," the number of immigrants and refugees is escalating. Immigration is a social determinant of health that can significantly affect care provision [10]. Additionally language differences, cultural beliefs, acculturation, as well as local profes-

sional norms and institutional resource constraints, must be taken into account when these guidelines are implemented across the planet [11,12]. These guidelines could not come at a more suitable time, for when numerous populations need updated recommendations, the digital age and this open access special issue will ensure their wide distribution.

The recent update to the "Guidelines for the Care of People with Spina Bifida" thrust scientifically-based SB care into this new era of dynamic and international collaboration among a worldwide community of clinicians and investigators. Of this global community, 23 countries were represented by those who participated in the Third World Congress of Spina Bifida Research and Care. Since that time, the *Journal of Pediatric Rehabilitation Medicine* has emerged as a global platform for the publication and dissemination of SB-related research. As we await the next World Congress of Spina Bifida Research and Care, this fifth SB-related special issue provides an open access collection of key guidelines and a number of innovative SB associated studies. It can be trusted that the guidelines and the accompanying original research published in JPRM will continue to serve as a catalyst for culturally-competent recommendations, as well as thoughtful investigation in order to improve the care among the diverse and aging communities of individuals affected with SB around the globe.

For additional information please visit: <https://content.iospress.com/journals/journal-of-pediatric-rehabilitation-medicine/13/4>.

Conflict of interest

The authors have no conflicts of interest to disclose.

References

- [1] Arshad Ali S, Baloch M, Ahmed N, Arshad Ali A, Iqbal A. The outbreak of Coronavirus Disease 2019 (COVID-19) – an emerging global health threat. *J Infect Public Health*. 2020 Apr; 13(4): 644–646. doi: 10.1016/j.jiph.2020.02.033.
- [2] Zaganjor I, Sekkarie A, Tsang BL, et al. Describing the prevalence of neural tube defects worldwide: a systematic literature review. *PLoS One*. 2016 Apr 11; 11(4): e0151586. doi: 10.1371/journal.pone.0151586.
- [3] Castillo J, Castillo H. Global health and chronic non-communicable conditions: spina bifida care across a worldwide community. *J Pediatr Rehabil Med*. 2017; 10(3–4). doi: 10.3233/PRM-170471.

- [4] Gandy K, Castillo H, Rocque BG, Bradko V, Whitehead W, Castillo J. Neurosurgical training and global health education: systematic review of challenges and benefits of in-country programs in the care of neural tube defects. *Neurosurg Focus*. 2020; 48(3): E14. doi: 10.3171/2019.12.FOCUS19448.
- [5] Dicianno BE, Beierwaltes P, Dosa N, et al. Scientific methodology of the development of the guidelines for the care of people with spina bifida: an initiative of the spina bifida association. *Disabil Health J*. 2020 Apr; 13(2): 100816. doi: 10.1016/j.dhjo.2019.06.005.
- [6] World Health Organization. World Health Organisation. (2001). International Classification of Functioning, Disability and Health (ICF). Geneva: World Health Organisation. *Int Classif*. 2001. doi: WHO/EIP/GPE/CAS/01.3.
- [7] World Health Organization. *How to Use the ICF: A Practical Manual for Using the International Classification of Functioning, Disability and Health (ICF)*; 2013. doi: 10.1016/j.dhjo.2015.03.002.
- [8] Hotez PJ, Damania A, Naghavi M. Blue marble health and the global burden of disease study 2013. *PLoS Negl Trop Dis*. 2016 Oct 27; 10(10): e0004744. doi: 10.1371/journal.pntd.0004744.
- [9] Castillo J, Gandy K, Bradko V, Castillo H. Language and latino immigrants living with spina bifida: social determinants of health—the missing dimension in quality of life research. *J Pediatr Rehabil Med*. 2019; 12(4): 345–359. doi: 10.3233/PRM-180586.
- [10] Castillo J, Brei TJ. Immigration and transition: changing demographics forecast the emerging trends in spina bifida care. *J Pediatr Rehabil Med*. 2019; 12(4): 337–338. doi: 10.3233/PRM-190016.
- [11] Olausen SJ, Renzaho AMN. Establishing components of cultural competence healthcare models to better cater for the needs of migrants with disability: a systematic review. *Aust J Prim Health*. 2016; 22(2): 100–112. doi: 10.1071/PY14114.
- [12] Suphanchaimat R, Kantamaturapoj K, Putthasri W, Prakongsai P. Challenges in the provision of healthcare services for migrants: a systematic review through providers' lens. *BMC Health Serv Res*. 2015 Sep 17; 15: 390. doi: 10.1186/s12913-015-1065-z.