

## Guest Editorial

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# Social determinants of health and spina bifida care: Immigrant and minority health in an era of quality of life and multicenter comparative analysis

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**Abstract.** Globally there is substantial variation in birth prevalence rates of neural tube defects. In the United States, for instance, the birth prevalence is seven cases per 10,000 live births, whereas in certain regions of Latin America, it has been reported to be as high as 96 cases per 10,000. While immigration from Latin America is often a result of social determinants, immigration itself can be understood as a social determinant of health (SDH). The Centers for Disease Control and Prevention has stated that when attempting to mitigate racial/ethnic health disparities, it should be remembered that SDH effectively determine longevity and quality of life (QOL). Subsequently, investigators have begun to recognize existing disparities through the use of the National Spina Bifida Patient Registry (NSBPR). In the face of these documented health disparities among minority populations with spina bifida, the need for timely and culturally-competent study of QOL among Hispanics/Latinos, who have the highest spina bifida prevalence, is self-evident. Furthermore, social variables have been linked with worse outcomes in national patient registries, illustrating the importance of accounting for SDH in multicenter comparative analysis. Therefore, accounting for these individual-level differences becomes even more critical, when making comparisons within SB care – a condition with a known ethnic/racial-gradient in incidence. As we face an increasingly global community, with growing travel and immigration, fresh approaches will be required, such as *community-based participatory research and culturally-competent learning collaboratives*, in order to address the challenges ahead.

**Keywords:** Social determinants of health, quality of life, community-based participatory research, immigrant health, minority health, three-hit model, learning collaborative

## 1. Introduction

Globally, it is estimated that more than 300,000 babies are born each year affected by neural tube defects (NTDs) [1]. Concurrently, there is substantial global variation in birth prevalence rates. In the United States (US), for instance, the birth prevalence is seven cases per 10,000 live births, whereas in certain regions of Latin America, it has been reported to be as high as 96 cases per 10,000 [2]. Even as Hispanics/Latinos immigrate into the US, they consistently have a higher birth prevalence of NTDs compared with other racial/ethnic

groups [3]. While immigration is often a result of social determinants, including political discrimination, poverty, education, and work-related prospects, immigration itself can be understood as a social determinant [4]. Within an ecological framework, recognizing that there are socioeconomic influences which impact and often help explain some of the divergent health outcomes found among communities – notably immigrant and minority subgroups – these factors have been termed *social determinants of health* (SDH) [5,6].

The Centers for Disease Control and Prevention (CDC) has defined SDH as the “conditions in the

environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality of life outcomes and risks” [7]. They have further stated that when attempting to mitigate racial/ethnic health disparities, it should be remembered that SDH effectively determine longevity and quality of life (QOL) [8]. Moreover, the CDC elaborates that healthcare delivery can be hindered if providers are not cognizant of *cultural context* (e.g., culture and language) and that a specific challenge of effectively working across cultures is linguistic obstacles. Therefore, it is imperative that healthcare providers support those with linguistic differences in order to ensure care is received by all members of a community [8], regardless of their English proficiency.

## 2. Social determinants of health and quality of life

Individuals affected by spina bifida (SB) are increasingly living well into adulthood. Concurrently, the assessment of SB-related disease burden on QOL has become essential in patient-centered care. In this setting, a previous systematic review of health-related QOL (HRQOL) assessments called for the exploration of social environments and HRQOL [9]. QOL has commonly been defined as “an individual’s perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, and concerns” [10]. Although cultural components such as language and value systems comprise basic elements of the social determinants of health leading to health-related outcomes, efforts towards incorporating these components into the study of QOL and SDH are only nascent in SB care [11]. However, this is increasingly crucial, as the estimated 55 million Hispanics/Latinos in the US are the fastest-growing demographic group [12] and nearly three out of every four Latinos speak Spanish at home [13]. In the face of documented health disparities among minority populations with SB [14], the need for timely and culturally-competent study of QOL among Hispanics/Latinos, who have the highest SB prevalence [3], is self-evident.

## 3. Social determinants of health and multicenter comparative analysis

Among individuals with SB, documentation of the lower rates of surgical management amid Hispan-

ics/Latinos to assist in bladder continence was first documented through a single-institution study [15]. Subsequently, decreased rates of surgical management to treat constipation and provide fecal continence among minority populations were documented through a national cohort [16]. Accordingly, investigators have begun to recognize existing disparities through the use of the National Spina Bifida Patient Registry (NSBPR) [17]. Modeled after the Cystic Fibrosis Foundation Patient Registry [18], the NSBPR is a partnership between the CDC and SB clinics throughout the US. Research through the NSBPR established that Non-Hispanic blacks were less likely than the other groups to have documented bladder/bowel continence; and Hispanics/Latinos were less likely than non-Hispanics [14]. The authors went on to state that after controlling for SB-related intrinsic characteristics, significant variations in outcomes associated with age, gender, race/ethnicity, and insurance status remained. They demonstrated that non-Hispanic blacks, Hispanics/Latinos, and those without private insurance had less favorable outcomes compared to other groups.

The fact that Hispanics/Latinos have been shown to have worse outcomes has significant implications for future research as this group increasingly comprises a significant percentage of the population [12]. Moreover, in an age of multicenter comparative analysis, differences in outcomes potentially rooted in social determinants must be thoughtfully studied. For example, socioeconomic variables have been linked with worse outcomes in both the US and United Kingdom’s cystic fibrosis national patient registries [19,20], illustrating the importance of accounting for SDH in multicenter comparative analysis. Accounting for these individual-level differences becomes even more critical, when making comparisons within SB care – a condition with a known ethnic/racial-gradient in incidence [3].

As with other NTDs, open SB (i.e., myelomeningocele) cases arise from a combination of genetic and environmental factors which are poorly understood. As a whole, the SDH framework helps us examine the multifactorial nature of the antecedents leading to the divergent myelomeningocele (MMC) related outcomes experienced by some minority populations. That is, for some subpopulations, precursors to poor MMC related outcomes may be best conceptualized through a “three-hit” model. Whereas the first two ‘hits’ are experienced prenatally (i.e., the neural tube lesion itself and its environmental exposure to amniotic fluid), the third ‘hit’ may involve combinations of additional genetic and/or non-genetic exposures, such as unfavorable SDH.

Promisingly, the Spina Bifida Association brought together content experts to update the SB healthcare guidelines, comprised of 25 areas of care delivery (available at: <http://www.spinabifidaassociation.org/guidelines>). These guidelines challenge professionals who care for minority communities to consider how “language, level of acculturation, and cultural constructs of care (e.g., concept of self-management) directly influence their understanding and reception of the health care message.” Additionally, in this era of QOL and multicenter comparative analysis, building trusting relationships among clinicians, researchers, and community members is needed to effectively serve this fast-growing vulnerable population. As with any stakeholder engagement activity, intentional energy must be invested to foment equitable collaboration and shared-decision making. Fresh approaches will be required, such as *community-based participatory research* and culturally-competent *learning collaboratives*, to develop respectful partnerships reflective of all lived experiences.

Fortunately, recent innovative studies regarding prenatal repair, HRQOL, and transitions across the lifespan thrust SB-related care into a new era of dynamic and prolific inquiry among an international 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 in March of 2017. Since that time, the *Journal of Pediatric Rehabilitation Medicine* (JPRM) has emerged as a global platform for the publication and dissemination of SB-related research. It can be trusted that the commentaries and original research published in JPRM will continue to serve as a catalyst for culturally competent QOL research as well as thoughtful investigation and comparative analysis of management practices in order to improve the care among the diverse community of individuals affected with SB around the world.

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