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Scorecard for spina bifida research, prevention, and policy: Score analysis by Human Development Index and WHO region

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ABSTRACT

The People and Organizations United for Spina Bifida and Hydrocephalus (PUSH!) Global Alliance created scorecards to rate country-level performance on spina bifida, including folate status among women of reproductive age; birth prevalence and mortality associated with spina bifida; prevention strategies; access to care; and the country's engagement in the UN Convention on the Rights of Persons with Disabilities. A total of 187 countries were examined based on a criteria-based scoring system represented by stars (http://www.pu-sh.org). This paper summarized scores by Human Development Index (HDI) classification spanning six World Health Organization (WHO) regions. For every indicator stratified by HDI classification, a greater proportion of 'Very High' and 'High' HDI countries scored a full star (highest performance) compared to countries in the 'Medium' and 'Low' HDI strata. A majority of countries in the South East Asia (SEARO) region received full stars for availability of published studies on folate status among women of reproductive age, and most countries in the European region scored full stars for surveying birth prevalence of spina bifida. Very few countries in the European (EURO) and SEARO region had full stars for prevention strategy for spina bifida through fortification. Overall, 90% of countries did not have published studies on spina bifida mortality. This is the first time country-level performance for spina bifida research, prevention and care, grouped by HDI and WHO region has been examined. Policy-makers and stakeholders can use our analyses as benchmarks in their efforts to improve spina bifida surveillance, prevention and care and to close gaps.

1. Introduction

In accordance with the Sustainable Development Goals (SDGs) target of ending preventable deaths of newborns and children under five years of age by 2030 (United Nations (UN), n.d.), reducing under five mortality remains a priority for many countries (World Health Organization, 2017). Progress was made in many countries during the Millennium Development Goals (MDG) era; however, realizing additional improvements in reducing newborn and child mortality necessitates directed attention to other causes of child mortality including birth defects (Lomazzi et al., 2014; Cha, 2017; Buse and Hawkes, 2015).

Globally, birth defects affect 1 in 33 infants, and in 2016, the United Nations (UN) report on child survival estimated that birth defects accounts for 9% of child deaths (United Nations Children's Fund (UNICEF), n.d.). Neural tube defects (NTD) are the second most common type of birth defects (Christianson et al., 2006). Spina bifida is one of the major and most common types of NTD and is considered a life-threatening birth defect affecting the development of the brain and spine. Fortunately, the majority of spina bifida-affected pregnancies are preventable. Empirical evidence shows that optimal folic acid intake (400 μg/day) by mothers before and during early pregnancy can effectively prevent spina bifida in most cases (Berry et al., 1999; Crider et al., 2014; Crider et al., 2018; WHO, 2015). Among the interventions that deliver folic acid to women of reproductive age, mandatory fortification of staple foods with folic acid is shown to be the most effective strategy (Atta et al., 2016).

Garnering support for birth defects surveillance and prevention, including that for spina bifida, has proved challenging, particularly in low- and middle-income countries (LMIC) (Zaganjor et al., 2016). The People and Organizations United for Spina Bifida and Hydrocephalus (PUSH!) Global Alliance was formed in 2014 to bring stakeholders and partners together to accelerate action to improve spina bifida and hydrocephalus surveillance and prevention, and to advocate for improved care and quality of life for those living with these conditions (Kancherla

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et al., 2017). PUSH! identified three major obstacles to improving spina bifida prevention and care upon which they focus their efforts: 1) lack of current and reliable data to advocate for prevention and care; 2) lack of cumulative knowledge of policies and implemented efforts to improve prevention and care; and 3) lack of awareness and efforts to address quality of life concerns for those living with spina bifida. In response, PUSH! developed a standardized spina bifida scorecard with data comparable across countries and within WHO-designated regions. The scorecards are publicly available at www.pu-sh.org, making evidence-based information on spina bifida prevention and care easily accessible to all. The scorecards also serve as an important and needed assessment tool for policy makers, advocates, and health care professionals, to promote national level dialogue on the prevention of spina bifida.

In this paper, we present the results of spina bifida scorecard analysis at the national level by Human Development Index (HDI) classification and by WHO region. These results provide an important viewpoint to help fill the information gap, foster country-level dialogue and support national efforts to begin or accelerate action.

2. Methods

The scorecards quantify country-level performance across selected indicators in the areas of surveillance, prevention, and care. Scorecard indicators were identified by the PUSH! Executive Committee which was comprised of clinicians, public health professionals, and epidemiologists. The committee identified six actionable areas to measure and rate country-level performance: 1) availability of published studies on folate status among women of reproductive age; 2) availability of published studies on birth prevalence of spina bifida; 3) availability of published studies on mortality associated with spina bifida; 4) current prevention strategy for spina bifida through mandatory or voluntary population-based grain fortification with folic acid (Food Fortification Initiative (FFI), n.d.); 5) access to care for those living with spina bifida, measured by proxy of number of neurosurgeons in the country per 1 million population (World Health Organization and the World Federation of Neurology, n.d.); and 6) the country's engagement in the UN Convention on the Rights of Persons with Disabilities as a measure to improve the quality of life for those living with spina bifida (United Nations, n.d.). The format of the scorecards and additional methodology are available in a previous publication (Kancherla et al., 2017).

Individual country performance was scored by each of the six indicators based on established rating criterion (Table 1). A “full star” (1 point) was assigned to countries that met fully the criteria for each respective indicator; a “half star” (0.5 point) was assigned to countries with evidence supporting only partial compliance in an indicator; and “no star” (0 point) was assigned to countries demonstrating no evidence to indicate compliance with an indicator. Scores for all six indicators were summed and an overall score was calculated for each country. A total score of six stars indicated that a country fully met all noted indicators measured by the scorecard. Scores for each indicator by country were shown, as were the cumulative score for the country. Based on those two scores, a set of generalized, high-level recommendations were provided for individual indicators to help guide countries consider areas for improved performance.

The current analysis aggregated and compared scores for countries by HDI classification and by WHO region. The HDI is defined as “a summary measure of average achievement in key dimensions of human development: a long and healthy life, being knowledgeable and have a decent standard of living” (United Nations Human Development Reports, 2018). The HDI is the geometric mean of normalized indices for each of the three dimensions. HDI ranking scheme classified countries into four tiers (i.e., very high, high, medium, low) of human development. WHO Region Classification groups WHO Member States into 6 WHO regions: Africa, Americas, South-East Asia, Europe, Eastern Mediterranean, and Western Pacific.

Scores were summarized for countries by year 2017 HDI classification and WHO region. Countries that did not have an HDI score were excluded from the summary analysis. Summary statistics including indictor-specific frequency and percent of countries with full, half and no star were identified by HDI classification and WHO region and examined to assess the distribution of scores. Statistical analyses were not undertaken to compare country scores due to low frequencies in individual strata.

3. Results

We scored 187 countries that had an HDI classification and an assigned WHO region. Of the six indicators evaluated in the scorecard, the signing and ratifying of the UN Convention of the Rights of Persons with Disabilities had the highest performance with 70% of the countries (N = 132) receiving a full star. The lowest performance was noted for availability of published population-based or large hospital-based mortality data (6 countries; 3.2%). For implementation of mandatory folic acid fortification policy that is aligned with WHO standards, 82 countries (44%) met the criterion for a full star (Fig. 1).

3.1. Findings by HDI classification

We examined country scores for all six indicators by HDI classification for 187 countries. Countries were grouped as Very High HDI (27%), High HDI (29%), Medium HDI (22%) and Low HDI (22%) (Table 2). For every indicator stratified by HDI, a greater proportion of Very High and High HDI countries scored a full star compared to countries in the Medium and Low HDI strata. Of the 30 countries that scored a full star for availability of published studies on folate status among women of reproductive age, none were in the low HDI strata. Approximately 90% of countries in the Low HDI stratum did not have available prevalence or mortality data. Irrespective of HDI status, only 6 countries had published studies to include in scoring for the indicator “availability of published studies on spina bifida associated deaths.” For the indicator on mandatory or voluntary population-based grain fortification, 56% of High HDI countries and Low HDI countries scored a full star. For the same indicator, a full star was received by 18% and 46% of the Very High HDI countries and Medium HDI countries, respectively. For the indicator on the number of neurosurgeons in the country per 1 million population, 82% of Very High HDI countries scored a full star but only 2.4% of the Low HDI had a full star. Majority of countries in each HDI strata received a full star for participating in the UN Convention on the Rights of Persons with Disabilities.

3.2. Findings by WHO regions

We examined country scores for all six indicators by WHO region (Table 3). Countries were grouped under WHO regions of Africa (47 countries), Americas (35 countries), Eastern Mediterranean (21 countries), Europe (51 countries), Western Pacific (23 countries) and South East Asia (10 countries). Of all the WHO regions, the South East Asia region had a high proportion of countries (7 out of 10) that received a full star for availability of published studies on folate status among women of reproductive age. On the contrary, only one country in the Africa region received a full star for the same indicator. Most countries in the Europe region scored full stars for published studies on birth prevalence of spina bifida or having population-based birth defects surveillance systems. Over 90% of countries in the world, irrespective of WHO regional status, did not have published studies on spina bifida-related mortality. For mandatory or voluntary population-based grain fortification indicator, all 35 countries in the Americas region scored a full star, followed by the Africa region where 23 out of 47 countries scored a full star. Very few countries in the Europe and South East Asia regions had full stars for prevention strategy for spina bifida through fortification. For the indicator on the number of neurosurgeons in the

Table 1
PUSH! scoring criteria.

Indicators	Star category	Description of scoring criterion
Availability of published studies on folate status among women of reproductive age	Full star	WHO data OR published population-based or large hospital-based data on RBC or serum folate levels (publication year: 1990 or upwards)
	Half star	Small studies on RBC or folate levels (publication year: 1990 or upwards); X = no studies on RBC or serum folate levels studies (publication year: 1990 or upwards)
	No star	No studies on RBC or serum folate levels studies (publication year: 1990 or upwards)
Availability of published studies on birth prevalence of spina bifida	Full star	Published population-based or large hospital-based prevalence data on live births, still births, elective terminations (publication year 2000 or upwards) OR existing birth defects surveillance system
	Half star	smaller hospital-based prevalence studies on live births, still births, elective terminations (publication year 2000 or upwards) OR small regional surveillance/official reporting
	No star	No published prevalence studies (publication year 2000 or upwards)
Availability of published studies on mortality associated with spina bifida	Full star	Published population-based or large hospital-based mortality data (publication year 2000 or upwards)
	Half star	Published smaller hospital-based mortality studies, small regional surveillance/official reporting (publication year 2000 or upwards)
	No star	No published mortality studies (publication year 2000 or upwards)
Current prevention strategy for spina bifida through mandatory or voluntary population-based grain fortification	Full star	Mandatory folic acid fortification policy is implemented and is aligned with WHO standards
	Half star	Voluntary folic acid fortification policy is implemented and is aligned with WHO standards
	No star	No mandatory or voluntary folic acid fortification policies.
Access to care for those living with spina bifida, measured by proxy of number of neurosurgeons in the country per 1 million population	Full star	Minimum of more than 1 neurosurgeon per 1,000,000 population
	Half star	0.2–1 neurosurgeons per 1,000,000 population
	No star	0–0.2 neurosurgeons per 1,000,000 population
The country's engagement in the UN Convention on the Rights of Persons with Disabilities as a measure to improve the quality of life for those living with spina bifida	Full star	Signed AND ratified the UN Convention on the Rights of Persons with Disabilities
	Half star	Signed only the UN Convention on the Rights of Persons with Disabilities
	No star	Neither signed nor ratified the UN Convention on the Rights of Persons with Disabilities.

Underlined words highlight specific PUSH! indicator label names.

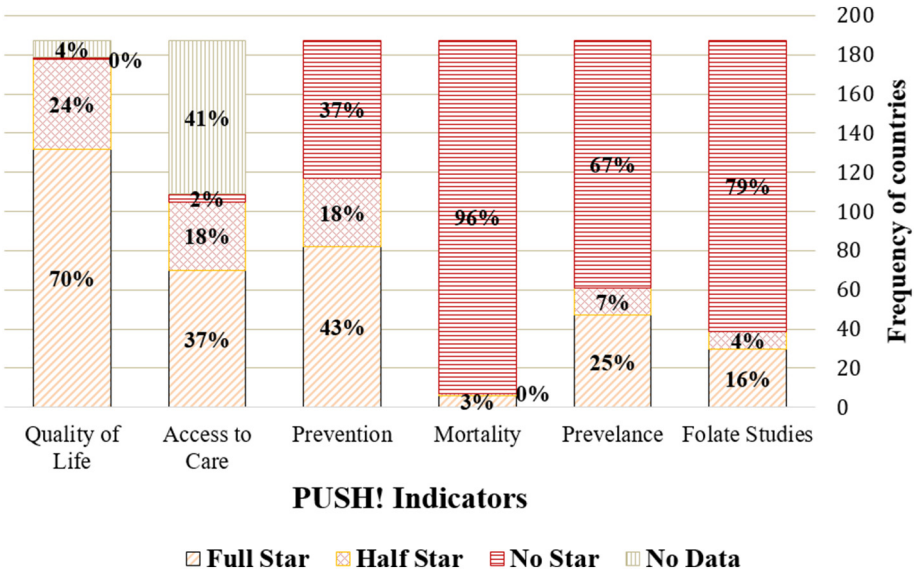

Fig. 1. Summary of distribution of frequency and percent of countries receiving full, half, or no stars, stratified by indicators, PUSH! scorecard project, 2015.

country per one million population, 41 out of the 51 countries in the Europe region scored a full star; whereas most of the countries in the Africa region had no data to examine this indicator. Most countries in the Africa, Americas, Europe and Western Pacific regions received a full star for the indicator measuring quality of life among those living with spina bifida as they had signed and ratified the UN Convention of the Rights of Persons with Disabilities.

3.3. Findings by cross-tabulating HDI classification and WHO regions

Finally, we cross-tabulated cumulative scores combining scores from all six indicators (ranging between 0 and 6) by WHO region and HDI (Table 4). A cumulative PUSH! score of 6.0 (equivalent to six full stars) would indicate that a country fully met the highest criteria (full stars) for each indicator in the scorecard. We identified that none of countries in this study received a cumulative score of 6.0 (Table 4). Consequently, the highest cumulative score was 5.5 in two countries in the Very High HDI classification and were in the Americas and Europe

Table 2
Summary of scores for indicators evaluated in PUSH! scorecards, stratified by Human Development Index.

Indicators	Scores	Human Development Index (HDI)[a]				Total N = 187
		Very high (N = 50) # countries (col %)	High (N = 55) # countries (col %)	Medium (N = 41) # countries (col %)	Low (N = 41) # countries (col %)	
Availability of published studies on folate status among women of reproductive age	Full star	13 (26)	10 (18)	7 (17)	0	30
	Half star	1 (2)	0	2 (5)	6 (15)	9
	No star	36 (72)	45 (82)	32 (78)	35 (85)	148
Availability of published studies on birth prevalence of spina bifida	Full star	29 (58)	10 (18)	5 (12)	3 (7)	47
	Half star	1 (2)	6 (11)	5 (12)	2 (5)	14
	No star	20 (40)	39 (71)	31 (76)	36 (88)	126
Availability of published studies on mortality associated with spina bifida	Full star	3 (6)	1 (2)	0	2 (5)	6
	Half star	0	0	1 (2)		1
	No star	47 (94)	54 (98)	40 (98)	39 (95)	180
Current prevention strategy for spina bifida through mandatory or voluntary population-based grain fortification	Full star	9 (18)	31 (56)	19 (46)	23 (56)	82
	Half star	11 (22)	7 (13)	10 (24)	7 (17)	35
	No star	30 (60)	17 (31)	12 (29)	11 (27)	70
Access to care for those living with spina bifida, measured by proxy of number of neurosurgeons in the country per 1 million population	Full star	41 (82)	20 (36)	8 (20)	1 (2)	70
	Half star	1 (2)	7 (13)	13 (32)	14 (34)	35
	No star	0	0	0	4 (10)	4
	No data	8 (16)	28 (51)	20 (49)	22 (54)	78
The country's engagement in the UN Convention on the Rights of Persons with Disabilities as a measure to improve the quality of life for those living with spina bifida	Full star	40 (80)	35 (64)	25 (61)	32 (78)	132
	Half star	9 (18)	18 (33)	11 (27)	8 (20)	46
	No star	0	0	1 (2)	0	1
	No data	1 (2)	2 (4)	4 (10)	1 (2)	8

col% = column percent; N = number of countries.
"Full star" is given to countries that fully met the criteria for an indicator; "Half star" is given to countries that partially met the criteria for an indicator; "No star" is given to countries that did not meet any of the criteria for an indicator; and "No data" is given to countries where no data was available to evaluate the criteria for an indicator. The PUSH! scorecards of 187 WHO countries were summarized; WHO countries that we not assigned a Human Development Index score were excluded. Underlined words highlight specific PUSH! indicator label names.
[a] United Nations human development reports. 2017. http://hdr.undp.org/en/content/human-development-index-hdi. Accessed on July 22, 2018.

Table 3
Summary of scores for indicators evaluated in PUSH! scorecards, stratified by WHO regions.

Indicators	Scores	WHO region						Total N = 187
		AFRO (N = 47) # countries (col%)	AMRO (N = 35) # countries (col%)	EMRO (N = 21) # countries (col%)	EURO (N = 51) # countries (col%)	SEARO (N = 10) # countries (col%)	WPRO (N = 23) # countries (col%)	
Availability of published studies on folate status among women of reproductive age	Full star	1 (2)	6 (17)	4 (19)	7 (14)	7 (70)	5 (22)	30
	Half star	6 (13)	0	2 (10)	0	0	1 (4)	9
	No star	40 (85)	29 (83)	15 (71)	44 (86)	3 (30)	17 (74)	148
Availability of published studies on birth prevalence of spina bifida	Full star	6 (13)	6 (17)	2 (10)	25 (49)	3 (30)	5 (22)	47
	Half star	1 (2)	6 (17)	6 (29)		1 (10)		14
	No star	40 (85)	23 (66)	13 (62)	26 (51)	6 (60)	18 (78)	126
Availability of published studies on mortality associated with spina bifida	Full star	2 (4)	2 (6)	0	1 (2)	0	1 (4)	6
	Half star	0	0	0	0	1 (10)	0	1
	No star	45 (96)	33 (94)	21 (100)	50 (98)	9 (90)	22 (96)	180
Current prevention strategy for spina bifida through mandatory or voluntary population-based grain fortification	Full star	23 (49)	35 (100)	12 (57)	6 (12)	2 (20)	4 (17)	82
	Half star	12 (26)	0	3 (14)	9 (18)	7 (70)	4 (17)	35
	No star	12 (26)	0	6 (29)	36 (71)	1 (10)	15 (65)	70
Access to care for those living with spina bifida, measured by proxy of number of neurosurgeons in the country per 1 million population	Full star	2 (4)	5 (14)	13 (62)	41 (80)	1 (10)	8 (35)	70
	Half star	15 (32)	9 (26)	4 (19)	0	5 (50)	2 (9)	35
	No star	2 (4)	0	2 (10)	0	0	0	4
	No data	28 (60)	21 (60)	2 (10)	10 (20)	4 (40)	13 (57)	78
The country's engagement in the UN Convention on the Rights of Persons with Disabilities as a measure to improve the quality of life for those living with spina bifida	Full star	40 (85)	25 (71)	12 (57)	40 (78)	0	17 (65)	132
	Half star	4 (9)	9 (26)	9 (43)	9 (18)	8 (80)	7 (30)	46
	No star	0	0	0	0	1 (10)	0	1
	No data	3 (6)	1 (3)		2 (4)	1 (10)	1 (4)	8

col% = column percent; N = number of countries.
"Full star" is given to countries that fully met the criteria for an indicator; "Half star" is given to countries that partially met the criteria for an indicator; "No star" is given to countries that did not meet any of the criteria for an indicator; and "No data" is given to countries where no data was available to evaluate the criteria for an indicator. The PUSH! scorecards of 187 WHO countries were summarized; WHO countries that we not assigned a Human Development Index score were excluded. WHO regions: AFRO = African; AMRO = Americas; EMRO = Eastern Mediterranean; EURO = Europe; SEARO = South-East Asia; WPRO = Western Pacific. Underlined words highlight specific PUSH! indicator label names.

Table 4
Summary of frequency of countries with cumulative PUSH! scores, cross-tabulated by Human Development Index and World Health Organization region.

Cumulative PUSH! score	Human Development Index[a]	World Health Organization region						Total number of countries
		AFRO	AMRO	EMRO	EURO	SEARO	WPRO	
0.5	Very high	–	–	–	–	–	–	0
(N = 8)	High	–	–	–	–	–	2	2
	Medium	–	–	–	–	2	1	3
	Low	2	–	1	–	–	–	3
	Total number of countries	2	0	1	0	2	3	
1.0	Very high	–	–	–	1	–	3	4
(N = 21)	High	–	1	–	4	1	1	7
	Medium	2	–	–	1	–	2	5
	Low	4	–	–	–	–	1	5
	Total number of countries	6	1	0	6	1	7	
1.5	Very high	–	–	–	1	–	–	1
(N = 23)	High	2	6	–	1	–	–	9
	Medium	1	–	–	2	–	2	5
	Low	5	1	1	–	–	1	8
	Total number of countries	8	7	1	4	0	3	
2.0	Very high	–	–	–	10	–	1	11
(N = 41)	High	1	6	–	4	–	1	12
	Medium	2	3	2	–	1	1	9
	Low	8	–	1	–	–	–	9
	Total number of countries	11	9	3	14	1	3	
2.5	Very high	–	–	4	3	–	–	7
(N = 35)	High	–	4	2	2	1	1	10
	Medium	1	3	1	–	1	1	7
	Low	9	–	2	–	–	–	11
	Total number of countries	10	7	9	5	2	2	
3.0	Very high	–	–	–	10	–	1	11
(N = 20)	High	–	3	2	1	–	–	6
	Medium	1	–	1	1	–	–	3
	Low	–	–	–	–	–	–	0
	Total number of countries	1	3	3	12	0	1	
3.5	Very high	–	1	–	3	–	–	4
(N = 14)	High	–	1	1	–	–	–	2
	Medium	1	1	1	–	2	–	5
	Low	3	–	–	–	–	–	3
	Total number of countries	4	3	2	3	2	0	
4.0	Very high	–	–	1	4	–	1	6
(N = 10)	High	–	–	–	1	1	1	3
	Medium	–	–	–	–	1	–	1
	Low	–	–	–	–	–	–	0
	Total number of countries	0	0	1	5	2	2	
4.5	Very high	–	–	–	1	–	–	1
(N = 4)	High	–	2	1	–	–	–	3
	Medium	–	–	–	–	–	–	0
	Low	–	–	–	–	–	–	0
	Total number of countries	0	2	1	1	0	0	
5.0	Very high	–	2	–	–	–	1	3
(N = 6)	High	–	–	–	–	–	1	1
	Medium	1	–	–	–	–	–	1
	Low	1	–	–	–	–	–	1
	Total number of countries	2	2	0	0	0	2	
5.5	Very high	–	1	–	1	–	–	2
(N = 2)	High	–	–	–	–	–	–	0
	Medium	–	–	–	–	–	–	0
	Low	–	–	–	–	–	–	0
	Total number of countries	0	1	0	1	0	0	
No data	Very high	–	–	–	–	–	–	0
(N = 3)	High	–	–	–	–	–	–	0
	Medium	2	–	–	–	–	–	2
	Low	1	–	–	–	–	–	1
	Total number of countries	3	0	0	0	0	0	

Overall PUSH! scores were calculated by summing the amount of stars countries were assigned.
"Full star" is equivalent to 1 point; "Half star" is equivalent to 0.5 point; and "No star" is equivalent to 0 point.
WHO Regions: AFRO = African; AMRO = Americas; EMRO = Eastern Mediterranean; EURO = Europe; SEARO = South-East Asia; WPRO = Western Pacific.
[a] United Nations Human Development Reports. 2017. http://hdr.undp.org/en/content/human-development-index-hdi. Accessed on July 22, 2018.

regions. The most common PUSH! score was 2.0, with 41 countries receiving the score, distributed by HDI classification of Very High (n = 11); High (n = 12); Medium (n = 9); and Low (n = 9), and among the WHO-regions of Africa (n = 11); Americas (n = 9); Eastern Mediterranean (n = 3); Europe (n = 14); South East Asia (n = 1); and Western Pacific (n = 3). Most of the remaining countries were concentrated in the lower score range, between 0.5 and 3.0. There were only 36 countries that scored a 3.5 or above, which was less than one-fifth of the countries included in the analysis (n = 187) (Table 4).

4. Discussion

This is the first time country-level performance for spina bifida research, prevention and care, grouped by HDI and WHO region has been examined to demonstrate country-level performance for spina bifida research, prevention and care using a select set of indicators. The results showed significant gaps and variations in how countries are meeting the indicators. None of the countries received the highest score of 6 stars. Of the 187 countries examined, the signing and ratifying of the UN Convention of the Rights of Persons with Disabilities had the highest performance. We examined this indicator as a proxy to a country's commitment to improve the quality of life of people with disabilities, including those with disabilities due to spina bifida. The lowest performance was noted on the indicator that examined availability of published population-based or large hospital-based mortality data. Less than half of the countries reviewed have implemented mandatory folic acid fortification policies in accordance with WHO standards. Mandatory folic acid fortification has the potential to save thousands of lives lost due to spina bifida each year and is an easily implementable national intervention. Scores varied by HDI classification and WHO region. Countries under “Very High” and “High HDI” classification received higher scores for the majority of indicators, but did not perform well for implementation of fortification, especially countries in the Europe region. The countries with “Low” and “Middle” HDI did not perform well on indictors related to prevalence studies. Almost all countries lacked studies on mortality associated with spina bifida. Our results demonstrate a need for countries to improve performance in all indicator areas to enable and advance policy, allocation of resources, and implementation of programs for spina bifida research, prevention and care.

There were several strengths to this analysis. The indicators examined in the scorecards were selected by a comprehensive group of experts in the field. We were able to conduct country-level analysis and examine the scores by HDI classification and WHO regional status for each country. As standard criteria were applied to produce scores for all countries, our findings allow comparability of scores between countries. These results can be used as a benchmark to track progress in addressing spina bifida surveillance, prevention and care in the future. The scores are universally simple to understand.

There are also some limitations to our analysis. The scores were based on existing databases, published studies, presence or absence of government policies and activities addressing NTD prevention, number of neurosurgeons per 1 million population in a country, and availability of information on a country's participation in the UN Convention on the Rights of Persons with Disabilities. We relied on published studies and grey literature to score country-specific performance on our selected indicators (Kancherla et al., 2017). The measures for indicators ‘access to care’ and ‘quality of life’ need to be improved so that they are based on current and more direct sources than what was accessible. Our measures include the number of neurosurgeons per 1 million population as a proxy for quality of care, and the UN treaty as a proxy for quality of life among those living with spina bifida. Similarly, publication bias and the lack of involvement of academia in publishing research on spina bifida limited the availability and number of studies we were able to abstract for scoring spina bifida mortality and folate status among women of reproductive age.

Evidence shows that benchmarks and report cards can help accelerate efforts to improve health programs and interventions. One example of such an effort is the March of Dimes prematurity report cards (March of Dimes, 2017) that have allowed the States in the US to recognize the gaps in their performance and advance policy and programs for reducing the rates of preterm births. Similarly, the MDGs by the UN in 2000 promoted national and global movement to improve eight population-based indicators by 2015 (United Nations, 2015), which contributed to the significant progress made at the population level as the resources of governments, donor agencies, and civil society organizations were consolidated to achieve these goals. The PUSH! scorecards are based on the same rationale given to the prematurity scorecards and MDGs. The scorecards are also in alignment with a recent call for action by global experts in the field of birth defects to accelerate national-level action to improve birth defects surveillance and prevention, and to advance the care and quality of life of affected individuals and families in order to reach SDGs on ending preventable deaths of newborns and children under 5 years of age (Darmstadt et al., 2016).

National level action backed by political will is necessary for decreasing spina bifida prevalence and associated disability. Even after the 2010 WHO resolution urging nations to devote efforts toward allocation of resources, birth defects remain neglected in prioritization of healthcare needs. Spina bifida is commonly assumed to be rare because of lack of data, which is reinforced by a lack of robust surveillance. We believe an opportunity exists to further birth defects research, prevention and care by integrating efforts into existing reproductive, maternal, newborn, child and adolescent health (RMNCH) programs.

In 2017, a technical consultation was convened by the Micronutrient Forum to address long standing challenges, and plan a way forward for NTD prevention in LMIC. The consultation by leading global experts produced a series of publications that address key challenges directly linked to the indicators captured in the PUSH! scorecards. These publications present the working group conclusions and a framework for action on how to improve maternal folate status to prevent NTD (Martinez et al., 2018) and how to use folate status in women of reproductive age as a basis for assessment of NTD risk in the offspring (Bailey and Hausman, 2018), a systematic analysis on global and regional prevalence of NTD for year 2015 (Blencowe et al., 2018), and a public health approach for preventing NTD through folic acid fortification (Garrett and Bailey, 2018). The technical consultation additionally proposed an integrated strategy based on triple surveillance, which includes surveying folate insufficiency, NTD prevalence and associated health outcomes in populations (Botto and Mastroiacovo, 2018). The systematic review of the consultation on the global folate status of women of reproductive age clearly underscored the lack of reliable, laboratory supported data on the folate status of women globally (Roger et al., 2018). There is a strong support for mandatory folic acid fortification demonstrating a positive return on investment and the potential to prevent thousands of child deaths (Hoddinott, 2018).

5. Conclusions

We provide the first ever indicators of country-level performance of spina bifida research, prevention and care. Overall, there were noticeable differences in performance of countries by their HDI status and WHO regions. Very few countries fully met the criteria for optimal research, prevention and care addressing spina bifida. There is a dearth of data and action in middle and low HDI countries where there is a highest prevalence of spina bifida. Regardless of HDI status, most countries in the EURO and SEARO regions do not implement mandatory folic acid fortification of staple foods for primary prevention of spina bifida. We know that the lack of country-level surveillance data has hampered efforts for improved population-based health outcomes related to birth defects. Global experts in the field of birth defects epidemiology recently called for immediate, national-level action to improve birth defects surveillance and prevention, and advance the care and quality of life of affected individuals and families (Darmstadt et al., 2016). Our effort to highlight differences in country standing by HDI classification and across and within WHO regions helps to strengthen an important action-oriented platform and further the necessary dialogue to begin and accelerate spina bifida research, prevention and care and to close gaps.

Conflict of interest

None.

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