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Analysis of a newly developed multidisciplinary program in the Middle East informed by the recently revised spina bifida guidelines

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Abstract.
PURPOSE: This paper describes the development and characteristics of a multi-disciplinary spina bifida clinic in Qatar considering the recently revised and globally available Guidelines for the Care of People with Spina Bifida (GCPSB).
METHODS: A retrospective chart review was performed on individuals in Sidra's multidisciplinary spina bifida clinic database from January 2019 to June 2020. Their electronic health records were reviewed for demographics, as well as neurosurgical, urologic, rehabilitation, and orthopedic interventions.
RESULTS: There were 127 patients in the database; 117 met inclusion criteria for diagnoses of myelomeningocele, meningocele, sacral agenesis/caudal regression, and/or spinal lipoma. Generally, Qatar is following GCPSB recommendations for multidisciplinary care. Consanguineous relationships, difficulties with access to urological and rehabilitation supplies and equipment, school access, and variable timing of neurosurgical closure were areas that demonstrated differences from GCPSB recommendations due to barriers in implementation.
CONCLUSION: The GCPSB recommendations are applicable in an international setting such as Qatar. Despite a few barriers in implementing some of the recommendations, this new multi-disciplinary spina bifida clinic demonstrates alignment with many of the GCPSB guidelines.

Keywords: Spina bifida, pediatric, multidisciplinary, global, Middle East

1. Introduction

Spina bifida (SB) is the second most common form of childhood motor disability and the most common complex congenital birth defect associated with long-term survival. Accurate reporting has been challenging and global rates of SB are variable. It has been estimated that global prevalence can range from 0.3-199.4 per 10000 births, with an estimate that at least 80% of global cases occur in settings where prevalence is greater than six per 10000 births [1]. From 1985-2009, Qatar's SB prevalence rate was 10.9 per 10000 births. Similar to other Gulf Cooperation Council countries, the lower regional rates are

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possibly related to a large expatriate population [2]. Given the complexity of SB and a significant global prevalence, the Guidelines for the Care of People with Spina Bifida (GCPSB) recommend a patient- and family-centered model in the context of coordinated care through the lifespan of patients to optimize care and outcomes [3]. While the delivery of coordinated care in a multidisciplinary setting in the United States can be challenging [4], it follows that adapting similar concepts in other global settings, such as Qatar, with a different healthcare system may be similarly challenging.

A multidisciplinary team model has historically been a common approach to the SB population. Qatar is a small, industrialized, wealthy country which has developed its own healthcare models and pathways over the years. Prior to 2010, individual sub-specialists at Hamad Hospital managed individuals with SB in their own respective clinic practices. The first multidisciplinary clinic was formed at Hamad Hospital in 2010. This clinic had participation from specialists in nephrology, urology, physical therapy, and occupational therapy. It served 80-90 patients in the local Doha area. In February 2018, Hamad Medical Center multidisciplinary SB clinic transferred to Sidra Medicine. The Sidra SB clinic is the only pediatric multidisciplinary SB clinic in the country. Sidra is a 400-bed, tertiary care hospital located in Doha, Qatar, that serves women and children. The first individuals with SB were evaluated at Sidra in 2017. Now, the Sidra multidisciplinary SB clinic serves more than 120 families.

Although the Spina Bifida Association's GCPSB provide a framework to optimize care for individuals with SB, it has been established that there are numerous ongoing areas in need of further research and improvement [5]. Sidra's SB clinic (SBC) shares many aspects of the multidisciplinary clinic model despite a few barriers.

The purpose of this study was to describe the development and characteristics of a multidisciplinary SB clinic in Qatar and describe alignment with, and barriers to, the recently revised and globally available GCPSB.

2. Methods

Sidra's SBC is a weekly, half-day clinic with four to five children scheduled per session every six to twelve months, depending on the needs of the individual. There is a team huddle of participating clinicians to review and discuss the patients before clinic began. The SBC team includes a nephrologist, urologist, pediatric physiatrist, physical therapist (PT), and primary nurse. An occupational therapist (OT) was also initially involved in the SBC. However, due to staffing limitations, they were unable to continue covering the clinic. After June 2020, a uro-therapist joined the team. The clinic involves face-to-face clinic visits in two separate rooms with two teams consisting of nephrology, urology, urology nurse, and, after 2020, the addition of the uro-therapist in one room. The physiatrist, PT, and/or OT examine patients in the other room. Neurosurgeons evaluate pre-selected patients or came to clinic if needed. Any other required specialists or ancillary services see patients in their individual clinics or in the SBC. Labs and basic imaging such as x-rays are done the same day as the SBC appointment. Urodynamics, brain imaging, and renal ultrasounds are typically scheduled separately.

Individuals who attended the SBC from January 2019 to June 2020 were eligible to participate in the retrospective study based on the list of those with SB in the clinic maintained by the nephrology team. They were included in the study if they had a documented electronic health record (EHR) diagnosis of meningocele (MC), myelomeningocele (MMC), spinal lipoma, or caudal regression/sacral agenesis. Excluded diagnoses were acquired spinal cord injury, a genetic syndrome as the primary diagnosis, hypotonia, and anorectal malformation. For the study, the list was de-identified and secured with password identification and locked files. Only the primary chart reviewers had access to the master list. Although best efforts were made to ensure accuracy, the EHR from involved clinicians included free text without templates for the clinic. The EHR included some auto-populated links for diagnoses, medical and surgical history, medications, and problem lists. It varied amongst specialists if these were used in the notes and/or updated regularly. Broad categories to capture data were established. EHRs, representing all subspecialists who were participating in clinic, were manually reviewed independently by two authors.

The pediatric physiatrist notes typically included family history, school history, and a section documenting if parents were related. The physiatrist documentation also included specific information on gait, Gross Motor Functional Classification System (GMFCS), adaptive equipment, scoliosis, orthotics, and orthopedic interventions. The GMFCS is traditionally for patients with cerebral palsy. In this study,

it was used to categorize mobility [6]. GMFCS was documented in the note according to the assessment of the pediatric physiatrist. Neurosurgery and pediatric physiatry notes were reviewed to assess SB level of lesion, which was classified as thoracic, lumbar, or sacral. The levels of lesion documented by neurosurgery and/or pediatric physiatry were based on clinical assessment of function. Imaging ordered was determined by review of EHR imaging results sections. Tethered cord (TC), shunt placement, spinal closure dates, and shunt revisions were obtained from neurosurgery notes. TC at Sidra was determined by MRI and clinical signs/symptoms, with collaboration from all specialists with neurosurgery if there were concerns. Neurosurgery decided on treatment based on correlation of MRI findings with clinical signs and symptoms, and urodynamic findings if needed.

Urology and nephrology documentation included various aspects of renal function, upper and lower tract function, bladder function, bowel function, and laboratory results performed at Sidra. These notes also included documentation of continence, catheterization schedules, bowel and bladder medications, and urinary tract infections (UTIs). Urinary continence was defined by urology as having dry times for two hours or more during the day and no overnight wetness. Fecal continence was defined as the capacity to pass stools with no involuntary leaks. The presence of incontinence was documented in correlation with either no treatment or urologic intervention such as medications, catheterizations, or enemas. UTI presence was based on documentation of having history of a UTI, but clarification of the time frame and frequency of UTIs was not consistently available in the urology or nephrology notes.

The statistician developed Microsoft Excel Pivot Tables to analyze the raw data for general assessment. Detailed statistical analysis was not possible given some unknown data fields and small group sizes. It was decided to report raw data results given these limitations and the descriptive nature of the study.

This retrospective single center chart review described the cohort of patients identified with SB seen at Sidra's SBC. Institutional Review Board (IRB) approval was obtained from the Sidra IRB Ministry of Public Health Assurance.

3. Results

There were 127 individuals identified in the SBC database during the study period for chart review. Ten individuals were excluded due to ineligible diagnoses. One hundred and seventeen patients met the criteria for diagnoses of MM, MMC, spinal lipoma, or caudal regression/sacral agenesis. One individual in the included category passed away during the study period.

The demographic and clinic characteristics are referenced in Table 1. There were 89 (76.1%) individuals diagnosed with MMC. There were 21 thoracic (23.6%), 49 lumbar (55.1%), and 19 sacral (21.3%) level pathologies. Twenty-eight (23.9%) individuals with non-MMC diagnoses were included. Of the participants, 62 (53.0%) were males and 55 (47.0%) were females. The individuals' ages ranged from newborn to 19 years. The average age was 8.1 years (standard deviation [SD] 4.93). Most patients were non-Qatari (73; 62.4%) vs Qatari (35; 29.9%); and nine (7.7%) individuals did not have documentation of nationality. The majority of non-Qatari patients were from African, Asian, and other Middle Eastern countries. Thirty percent of parents ($n = 35$) had a documented consanguineous relationship and 17 (14.5%) parents had an unknown documentation for parent relationship history. The most common relationship of parents were first cousins (65.7%). Five (4.3%) children were additionally diagnosed with a secondary genetic syndrome and five (4.3%) had siblings with a "disability." Some of the sibling disorders included speech delay, autism, cerebral palsy, tetralogy of Fallot, G6PD deficiency, Dandy Walker syndrome, and leukemia. There was one individual who had two siblings with SB. Fifty-nine out of seventy (84.3%) children aged six years or older were attending school.

From the urologic standpoint (Table 2), 69 (59.0%) individuals performed clean intermittent catheterizations (CIC) with the most common frequency being four times a day. Fifty (60.2%) children aged 4-19 years were noted to be urine incontinent by documentation in the urology and nephrology notes; 33.7% were continent and 6.0% had an unknown continence status. In cases of deterioration of the upper tracts (defined as recurrent pyelonephritis or increase of hydro-ureteronephrosis) and/or persistence or new onset of incontinence after four years of age, a urodynamic study was performed. Almost half (46.2%) of the patients had at least one urodynamic study performed, and 13.7% of these had video urodynamics. Surgical treatment was offered and performed in individuals whom the urologist deemed as non-responsive to medical therapy with or without a CIC program, and thus fourteen

Table 1
Demographic and clinical characteristics

	N	%		N	%
Total	127		**Full Term vs Premature**	**N=117**	
Included	117		Full term 37-40 weeks	87	74.4
Excluded	10		32-36 weeks	9	7.7
			28-31 weeks	1	0.9
Gender	**N=117**		<28 weeks	3	2.6
Male	62	53	Unknown	17	14.5
Female	55	47			
			6yo or older school	**N=70**	
Age	1-19yo[1]		In school	59	84.3
Average age	8.1yo		Not in school	8	11.4
SD	.93		Unknown	2	2.9
			Not applicable	1	1.4
			6yo or older type of school	**N=62**	
Nationality	**N=117**		Regular school	45	76.3
Qatar	35	29.9	Special needs class	3	5.1
Egypt	13	11.1	Integrated classroom	2	3.4
Sudan	12	10.3	Special needs school	1	1.7
Pakistan	11	9.4	Unknown	7	11.9
India, Jordan, Syria (each)	6	5.1	Not applicable	1	1.6
Algeria, Iraq, Philippines, UK, USA, SO (each)	2	1.7	**Consanguineous**	**117**	
AU, CA, CL, CO, ET, LK, YE (each)	1	0.9	Yes	35	29.9
Unknown	9	7.7	No	65	55.6
			Unknown	17	14.5
Diagnoses Included	**N=117**				
MMC	**89**	**76.1**	**Nationality & Consanguinity**	**N=35**	
Thoracic	21	23.6	Qatar	14	40
High Lumbar (L2)	13	14.6	Sudan	6	17.1
Mid Lumbar	24	27	Pakistan	4	11.4
Low Lumbar	12	13.5			
Sacral	19	21.3	**Parent Relationship**	**N=35**	
			1st cousins	23	65.7
Non-MMC	**28**	**24%**	2nd cousins	4	11.4
–Caudal reg/Sacral agenesis	8	6.9	3rd cousins	2	5.7
–Meningocele	4	3.4	Other	3	8.6
–SB Occulta/Lipoma	16	13.7	Unknown	3	8.6
			Other	**N=117**	
Diagnoses Excluded	**N=10**		Tracheostomy	3	2.6
Acquired spinal injury	6	60	Unknown tracheostomy	1	0.9
Other	4	40	Gastrostomy tube	5	4.3
			Genetic/other syndrome	5	4.3
			Sibling with a disability	5	4.3

yo = years old, SD = standard deviation, UK = United Kingdom, SO = Somalia, AU = Australia, CA = Canada, CL = Chile, CO = Colombia, ET = Ethiopia, LK = Sri Lanka, YE = Yemen, MMC = myelomeningocele, reg = regression, SB = spina bifida. One individual passed away, denoting not applicable in some categories for school.

individuals (11.9%) underwent surgical treatment. Surgical treatment included intra-detrusor injections with botulinum toxin ($n = 2$), Mitrofanoff channel construction ($n = 9$), and Mitrofanoff combined with bladder augmentation ($n = 1$). Malone antegrade conduit for enema was performed in three individuals, with one of them in combination with bladder augmentation and Mitrofanoff. From the neurosurgical standpoint (Table 3), 66 (74.2%) individuals with MMC had a ventricular peritoneal shunt (Table 3). Fifteen of 21 (71.4%) individuals with shunts had at least one shunt revision. Thirty-five of 89 individuals with MMC (39.3%) had closure of their spinal defect in the first two days of life, fourteen (15.7%) had spinal closure on days 3-7, and 18 (20.2%) individuals had closure after one week of age. Twenty-four (20.5%) individuals were diagnosed with TC, and the majority of these were among children with sacral level lesions. Eleven (45.8%) underwent detethering surgery. There was no history of prenatal surgeries performed on individuals in the SBC.

Table 2
Urology/nephrology findings

	N	%		N	%
CKD	**117**		**Bowel Surgery**	**N=117**	
Yes	3	2.6	Yes	3	0.9
CKD Stage	N=3		No	114	97.4
Stage 3	3		**Bowel Surgery Type**	**N=3**	
			MACE Conduit	3	
CIC	**N=117**		Bowel Surgery at Sidra	1	
Yes	69	58.9			
No	48	41.0	**Bladder Surgery**	**N=117**	
			Yes	14	11.9
CIC 4-11yo	**N=57**		**Bladder Surgery Type**	**N=14**	
Yes	39	68.4	Mitrofanoff	9	64.3
No	18	31.6	Other	3	21.4
			Bladder Augmentation	1	7.1
CIC 12-19yo	**N=26**		Unknown	1	7.1
Yes	21	80.8	**Bladder Surgery Location**	**N=14**	
No	5	19.2	Sidra	5	35.7
			Not performed at Sidra	8	57.1
CIC Frequency	**N=69**		Unknown	1	7.1
1x/day	1	1.4			
2x/day	2	2.9	**Botox Injections**	**N=117**	
3x/day	10	14.5		2	1.7
4x/day	27	39.1	**UTI**	**N=117**	
5x/day	16	23.2	Yes	27	23.1
More than 5x/day	9	13	No	78	66.7
Overnight Catheter	1	1.4	Unknown	12	10.3
Unknown	3	4.3			
			Urologic Imaging/Tests		
Incontinence 4-19yo	**N=83**		**Renal Ultrasounds**	**N=117**	
Yes	50	60.2	Yes	111	94.9
No	28	33.7	No	6	5.1
Unknown	5	6.0	**Video Urodynamic**	**N=117**	
			Yes	16	13.7
Incontinence 4-11yo	**N=57**		No	101	86.3
Yes	36	63.2	**Regular Urodynamic**	**N=117**	
No	17	29.8	**Yes**	79	67.5
Unknown	4	7.0	No	38	32.5
			VCUG	**N=117**	
Incontinence 12-19yo	**N=26**		Yes	36	30.8
Yes	14	53.8	No	81	69.2
No	11	42.3	**DMSA Scan**	**N=117**	
Unknown	1	3.8	Yes	32	27.4
			No	85	72.6

CKD = chronic kidney disease; CIC = clean intermittent catheterization; yo = years old; MACE = Malone antegrade conduit enema; VCUG = voiding cystourethrogram; DMSA = dimercapto succinic acid.

From the rehabilitation standpoint (Table 4), 40.2% individuals used orthotics. Twenty-six (22.3%) individuals used assistive devices, such as walkers or forearm crutches. Forty-eight (41.0%) individuals used a wheelchair for mobility. Thirty-one children (26.5%) had a history of lower extremity orthopedic surgery. Seventeen had scoliosis documented in their problem list and/or physical exam and 14.5% of these had spinal surgery. Twenty-seven (23.1%) received solely physical therapy, one received two therapy services, and one received three therapy services.

4. Discussion

The GCPSB provide in-depth recommendations for all aspects of SB care. In this discussion, a few topics will be highlighted as they correlate to trends observed in the Sidra SBC. The GCPSB promote patient- and family-centered care that incorporates cultural contexts. Qatar's population reflects an international community, with the majority of families served in the SBC being non-Qatari. This is in alignment with the demographics of the country where 85% of the total population are ex-patriates.

Table 3
Neurosurgery data

	N	%		N	%
Shunt	**N=89**		**Tethered Cord**	**N=117**	
MMC	66	74.2	Yes	24	20.5
Sidra Placement	4	4.5	No	93	79.5
Outside Hospital	62	69.7	**Detethering Surgery**	**N=24**	
No Shunt	23	25.8	Yes	11	45.8
Shunt Revision MMC	**N=66**		No	13	54.2
Yes	21	31.8	**Detethering Location**	**N=11**	
No	40	60.6	Sidra	6	54.5
Unknown	5	7.6	Other Location	5	45.5
# of Shunt Revisions	**N=21**		**Detethering Neurol Level**	**N=11**	
1	15	71.4	Low Lumbar	1	9.1
2	3	14.3	Mid Lumbar	2	18.2
More than 2	3	14.3	Sacral	8	72.7
Spinal Closure MMC	**N=89**		**Brain and Spine Imaging**	**N=117**	
1 day	21	23.6	**MRI Head**		
2 days	14	15.7	Yes	38	32.5
3 days	5	5.6	No	79	67.5
4 days	2	2.2	**MRI Spine**	**N=117**	
6 days	1	1.1	Yes	51	43.6
1 week	6	6.7	No	66	56.4
>1 week	18	20.2	**CT Head**	**N=117**	
Unknown	22	24.7	Yes	19	16.2
			No	98	83.8
MMC Spinal Closure Hospital	**N=89**		**Shunt Series**	**N=117**	
Other Hospitals	73	82.0	Yes	8	6.8
Sidra	5	5.6	No	65	55.6
Hamad Hospital Doha	4	4.5	Not Applicable	44	37.6
Unknown	4	4.5			
Not Applicable	3	3.4			
In Utero Repair	**0**				

MMC = myelomeningocele, # = number; Neurol = neurologic.

Consanguinity is common in Qatar and the Gulf region, and 40% of Qatari National SBC parents were documented as consanguineous. In Saudi Arabia's SB registry, 46% of parents had a consanguineous relationship [7]. A study on consanguineous marriages in Qatar in 2004-2005 demonstrated 51% consanguinity, with higher rates in low and high socio-economic groups [8]. The rate for Qatari's in the current study sample was lower than this previous Qatar study, although socioeconomic status was not documented in the current study. In 2012, another study by Bener of Qatar on neural tube defects showed that 36.7% of parents were consanguineous, which is closer to rates observed in the SBC [2]. Due to higher rates of consanguineous relationships, consideration of cultural differences should be maintained when caring for families and children with SB, so that medical providers are sensitive to their needs and can educate families on genetic factors that influence SB and other disorders. This aspect of the demographics is an important consideration in the spectrum of the GCPSB in terms of prenatal discussions, disability, survival, and outcomes in a global context [3].

The GCPSB state that, between three and five years of age, discussions should be held for preparing families for preschool and any services needed to make this transition successful. By school age, the guideline recommends monitoring children within the school system for additional educational support. In Qatar, preschool starts at four to five years of age and kindergarten starts at five to six years of age, depending on the child's birthday. All Qatari children are required to be in school by six years of age. Expatriate children may have barriers to enrollment before six years of age. However, it was found that 84.3% of children over six years old were in school, with only 11.4% of school-age children (over six years) not enrolled. There were only four (19.2%) children between three to five years old enrolled in school. This left eighteen (69.2%) of the preschool age group not in school, with 11.5% of unknown school status. In comparison to other international settings, this statistic was better, but in comparison to US National

Table 4
Rehabilitation findings

	N	%		N	%
Orthotics	**N=117**		**GMFCS**	**N=117**	
None	64	54.7	GMFCS I	45	38.5
AFO	29	24.8	GMFCS II	8	6.8
KAFO	9	7.7	GMFCS III	15	12.8
HKAFO	5	4.3	GMFCS IV	31	26.5
RGO	2	1.7	GMFCS V	18	15.4
Orthotic Shoes	2	1.7			
GRAFO	1	0.9	**Wheelchair & Neurol Level**	**N=48**	
SMO	1	0.9	Thoracic	17	35.4
Inserts	1	0.9	High Lumbar (L2)	9	18.8
Shoe Lift	1	0.9	Mid Lumbar (L3)	16	33.3
Unknown	2	1.7	Low Lumbar (L4, L5)	9	18.8
			Sacral	5	10.4
Assistive Device	**N=117**				
None	91	77.8	**GMFCS & Wheelchair**	**N=48**	
Walker	16	13.7	GMFCS I	1	2.1
Forearm Crutches	5	4.3	GMFCS II	2	4.2
Stander	**5**	4.3	GMFCS III	6	12.5
			GMFCS IV	27	56.3
Wheelchair	**N=117**		GMFCS V	12	25.0
Yes	48	41.0			
No	69	59.0	**GMFCS & Assist Device**	**N=117**	
			GMFCS I	**N=45**	
Spine Surgery	**N=117**		- none	45	100
Yes	5	4.3	**GMFCS II**	**N=8**	
No	112	95.7	- forearm crutches	1	12.5
Spine Surgery at Sidra	**N=5**		- none	7	87.5
Yes	5		**GMFCS III**	**N=15**	
			- forearm crutches	4	26.7
LE Ortho Surg	**N=117**		- none	3	20
Yes	31	26.5	- stander	1	6.7
No	86	73.5	- walker/gait trainer	7	46.7
Ortho Surg at Sidra	**N=31**		**GMFCS IV**	**N=31**	
Yes	5	16.1	- none	18	58.1
No	26	83.9	- stander	4	12.9
			- walker/gait trainer	9	29.9
Therapy	**N=117**		**GMFCS V**	**N=18**	
None	88	75.2	- none	18	100
PT alone	27	23.1			
2 therapies (PT/OT or SLP)	1	0.9	**Fracture History**	**N=117**	
3 therapies (PT/OT/SLP)	1	0.9	Yes	8	6.8

AFO = ankle foot orthosis, KAFO = knee ankle foot orthosis, HKAFO = hip knee ankle foot orthosis, RGO = reciprocating gait orthosis, GRAFO = ground reaction articulated foot orthosis, SMO = supramalleolar orthosis, LE = lower extremity, PT = physical therapy, OT = occupational therapy, SLP = speech language pathology, GMFCS = gross motor classification system, Neurol = neurological.

Spina Bifida Patient Registry (NSBPR) data, school rates remained low for preschool ages (Table 1). In Saudi Arabia's SB registry, 24% of patients were in school, 5% never attended school, and 2% of patients in school were considered "disabled." The definition of "disabled" included patients with "neurological or mental deficits" [7]. Similarly, in Uganda, 17.9% of children with SB were not in school while all of their siblings were reported to be in primary school [9]. The Individuals with Disabilities Education Act allows for free and appropriate public education for all eligible children with a disability in the US. This permits children to start school at three years old. The US NSBPR reported that, of school-age participants, 39.5% were in pre-school and 55.5% were in primary/secondary school, which implies that at least 95% of US individuals with SB were enrolled in school [10]. The US school experience for individuals with SB is certainly disparate to other global settings.

Following the GCPSB in relation to education can be challenging due to barriers that arise from educational policies and access to schools. Although inclusion is discussed and is part of the Ministry of Education's strategic plan in Qatar, many chil-

dren with a disability do not have access to public schools. Some children can only attend schools that are exclusively for those with a disability. Those who attend these schools are not integrated with neurotypically developing children. The 2019-2020 Ministry of Education's Department of the Educational Policy and Research-Educational Statistics Section report in Qatar listed four private schools for disabled children and four public schools for disabled children [11]. The 2020-2021 report showed that the total number of disabled students enrolled in school increased to 2623 from 2291. These reports did not include a definition of disability, nor information on the type of diagnoses [12]. Since the time of this chart review, Qatar has increased the number of "inclusive" schools to 66 [13].

Access to schools in Qatar for children with disability can be challenging for a variety of reasons. When children with disability enroll in school, there are other issues that may arise. Barriers to education for individuals with SB in Qatar include the following: schools are often not wheelchair accessible, lack of nursing support or facilities to assist with bowel and bladder programs, arbitrary exclusion criteria, limited public school options, lack of adaption of curricula for special needs individuals, lack of health literacy of staff who feel that children with SB present a fall risk, cost barriers, and language barriers. Some schools are now being retrofitted for accessibility, but this remains a barrier at older schools [14]. Due to many barriers, implementation of the educational recommendations for individuals with SB in the multidisciplinary clinic according to the GCPSB remains a challenge in Qatar, but there is progress.

The GCPSB recognize the essential role of neurosurgery to optimize neurological functional and developmental outcomes. From the neurosurgery perspective, 66 (74.2%) individuals with MMC had ventricular shunts placed (Table 3). There is an NSBPR profile article that describes an overview of the demographics of the registry. In the US NSBPR, 79.9% of individuals with MMC had a shunt [10]. Qatar's shunt placement values are similar to the US NSBPR data. The GCPSB recommend spinal closure within 48 hours after birth in MMC patients [3]. This review demonstrated variability in the time of MMC closure, with 39.3% being closed in the first two days of life, 15.6% being closed on day of life 3 –7, and 20.2% being closed after one week (Table 3). Similarly, a study in Saudi Arabia showed 43.6% of its SB registry patients having closure in the first three days of life [7]. These findings in Qatar may reflect the international population served, as many procedures were performed in other countries that may have barriers to healthcare access and procedures. They also may reflect anecdotal recall of events from parent history for children born outside of Qatar.

TC was identified in 20.5% of individuals, with surgery occurring in 11 (45.8%) individuals (Table 3). Global incidence of TC is 14-32% [15]. According to the US NSBPR profile, 21.5% of individuals underwent TC surgery [16]. Qatar's rates were higher at 45.8%. However, of the de-tethering surgeries, only six were performed at Sidra. There are likely variable criteria in de-tethering decision-making given the diverse countries represented. Sidra's neurosurgery department collaborated in team discussions around decisions to perform surgery on symptomatic patients.

Having access to neurosurgery follows GCPSB recommendations. However, there were scheduling limitations as neurosurgery staff could not be present for every patient for the entire clinic. Neurosurgeons were available to see patients in the team clinic on an "as needed" basis only. Otherwise, patients were regularly followed in their individual neurosurgery clinics. Neurosurgery facilitated decision-making based on imaging, and as per the GSPCB, imaging was regularly ordered, with MRI being the most commonly used. Globally, in less developed countries, there may be institutions that do not have, or only have limited access to, imaging techniques such as MRI to guide interventions and management. Overall, neurosurgical care followed general multidisciplinary SB clinic recommendations for surgical management and imaging with a few noted differences.

In relation to mobility and rehabilitation, the GCPSB goals include developing expectations for mobility based on age and neurologic level. Mobility devices and therapy interventions are to be incorporated in the care of individuals with SB. However, access and implementation are difficult in Qatar. Custom ankle-foot orthoses are either manufactured at the local public hospital or are measured at Sidra, fabricated abroad, and then shipped back and custom fit locally. Above knee bracing options are fabricated at a local public hospital as Sidra does not have an affiliated orthotics laboratory. The World Health Organization (WHO) estimates that only one in 10 people in need have access to assistive devices such as orthoses due to cost barriers, lack of awareness, availability, trained personnel, policy, and financing barriers [17].

Mobility devices such as walkers and standers can be difficult to obtain in Qatar due to limited style options, limited supply, and out-of-pocket costs. The GMFCS has traditionally been used in individuals with cerebral palsy. It provides details for age, assistive device, and mobility, thus, the use of GMFCS for this review. Since the time of this article, the Myelomeningocele Functional Classification was introduced. There were a few patients in the GMFCS I or II levels who were documented as having forearm crutches and/or wheelchair but did not use these devices for mobility. Of all patients, 41.0% used wheelchairs, and as expected, children with GMFCS levels IV-V (non-ambulators) demonstrated the highest percentage of wheelchair use at 81.3%. Many wheelchairs needed repairs or growth modifications or were poorly fitted, and some were donated or borrowed from family or friends. Barriers to obtaining wheelchairs include cost, time to procure, and limited available models.

This is similar to global statistics from the WHO and United Nations' International Children's Emergency Fund, which surveyed 330000 persons in 35 countries for assistive technology access through self-reported population surveys. They estimate there are more than 2.5 billion individuals who would benefit from assistive products. However, global inequity exists in relation to access, with access to adaptive equipment ranging from 3-90%, depending on the country. For children, only 5–15% of assistive technology needs are met [18]. Similarly, at least 70 million people globally need a wheelchair, but only 5–15% have access to them. Barriers cited were high cost, limited availability, lack of adequate financing, lack of awareness, and lack of suitably trained personnel to provide assistive equipment [19]. Additionally, some public buildings and schools are not fully accessible with large curbs, limited accessible bathrooms, non-standard ramps, and no elevators [20]. Although clinicians and therapists recognize the need for mobility devices and adaptive equipment as per the GCPSB, there remains ongoing work in making such devices more easily accessible in the community.

From the urologic perspective, primary GCPSB goals are to maintain normal renal function throughout life, maximize urologic independence, and achieve urinary continence as early as socially acceptable. This chart review included three individuals with chronic kidney disease (Table 2). There are variable rates in the literature for the progression to chronic kidney disease. Kanaheswari reviewed 56 pediatric SB charts and found that six patients progressed to chronic disease. They had a history of dilating vesicoureteral reflux, recurrent UTIs, or pyelonephritis. They also cited late referrals as a factor in sub-optimal renal care [21]. Another study in Saudi Arabia reviewed 33 pediatric individuals with SB, and one patient was documented to have renal disease. The authors cite possible cultural factors in which family may not readily accept the concept of CICs. Additionally, they note a lack of knowledge by healthcare professionals causing a delay in starting CICs [22]. As discussed below, cultural factors were also thought to influence aspects of urologic care in Qatar. Urodynamics, renal ultrasounds, oral medications, and laboratory assessments were routinely utilized as per GCPSB's primary urology goal of maintaining normal renal function throughout the lifespan.

Secondary urology goals of the GCPSB include establishing a care program to optimize urinary independence with CICs. Fifty-nine percent of individuals were noted to have CIC as part of their bladder program. The US NSBPR profile similarly reports 69.0% catheterization rates [10]. In Uganda, 81.3% of individuals practiced CIC [9]. Similar to the US NSBPR data, Mitrofanoff was the most common bladder surgery [10]. Having both urology and nephrology involved in the SBC was a unique and ideal feature of Qatar's multidisciplinary SB clinic. However, despite this, cultural contexts and lack of dedicated public spaces can represent a barrier for effective bladder and bowel management plans. In a SB patient survey previously conducted by the SBC, families identified access barriers including the cost of urologic supplies and non-centralized supply locations. The current study did not examine the relationship between CIC and lesion level, intellectual function, gender, or age at independence of catheterizations. Castillo and colleagues determined the average age for independent catheterization was 9.45 years for US children. Female gender or higher lesion level made independence with catheterizations more difficult [23]. Although this data was not specifically collected, it is the observation of the SBC clinicians that self-catheterization occurs late in the teenage years, or not at all, with several teenagers being catheterized by a parent or outside caregiver. It is speculated that this may be due to some of the barriers in obtaining supplies and cultural differences. The study also did not examine if urological interventions improved fecal and bladder continence over time.

Although the GCPSB emphasize care coordination, there is no set structure on how this should be implemented. There are also broad recommendations of specific team members who can be involved in the SBC. The multidisciplinary clinic model for SB patients started as March of Dimes polio clinics decreased and the funds transitioned to SB. At that time, subspecialists such as urologists and neurosurgeons were added to the existing teams of orthopedists, urologists, and PTs. There is great variation in how multidisciplinary clinics in spina bifida function [4]. The team at Sidra's SBC formed based on available staff and resources with the acknowledgement and goal of at least providing immediate access to neurosurgery, urology/nephrology, and rehabilitation. Other specialists could be accessed on an "as needed" basis.

Having a care coordinator has been highlighted and guidelines for care coordination have been established [24]. The ideal role of care coordinators includes facilitating scheduling, referrals, and communication of team recommendations to families. This role can be covered by a single person in nursing, a single practitioner, or the entire SB team [25]. Common specialties that may serve in a coordinator role include general pediatricians, developmental pediatricians, or physiatrists [26]. Sidra utilizes a team approach for care coordination as there is not a single, designated coordinator. However, nephrology is the founding specialty and the nephrology/urology nurses partially serve in this role. Staff and funding limitations are barriers for establishing a dedicated coordinator at SBC.

The topic of providing care across the lifespan of patients with SB, which includes the transition into adult care, is a growing area of discussion. The GCPSB now include a section on transition care. In the data used in this study, the SBC was serving individuals up to the age of 19 years. This study did not track transition aspects of care. In adult care, there is more fragmentation of care with increased use of inpatient and emergency services [27]. There may be limited availability of clinicians with experience with the SB population and financial/insurance barriers [27]. There are transition questionnaires that have been developed to make the transition to adult care easier, but consistent, meaningful integration into practice has been difficult in many settings [28]. Options for transition care include providing lifelong care, coordinated transfer to adult primary care providers at an affiliated institution, or joint visits with adult healthcare providers [29]. Sidra traditionally transitions individuals at 18 years of age to identified adult specialists. There is a coordinated joint visit with adult urologists and nephrologists at Sidra's SBC at the last visit before transition in which a medical summary is provided. The patients are then followed by urology/nephrology, neurosurgery, and physical medicine and rehabilitation separately at the adult hospital. For the patients in this study, Sidra SBC specialists had working relationships with adult specialists to facilitate transition referrals given that there was only one primary adult hospital where patients could transition. Also, Sidra has started to incorporate objective transition questionnaires for individuals before transition. However, remaining sensitive to cultural and language barriers in communicating and establishing transition goals is an ongoing challenge at the SBC.

The GCPSB provide a comprehensive framework for the care of SB patients. Clinicians in the SBC at Sidra make appropriate recommendations aligned with the GCPSB. Some aspects of the GCPSB have been difficult to achieve to date at the SBC and can be observed in other multidisciplinary clinics, including those in developed countries. However, despite these limitations, the GCPSB are generally being followed in Qatar. More importantly, dialogue on how to improve some of the barriers to care has been initiated. Recommendations also must be adapted to cultural values of the community served. For example, Qatar is improving community education on the potential effects of consanguinity in family planning. Given the high consanguineous rates in this review, prenatal genetic education and discussion for families may be a recommendation from the GCPSB that is prioritized. Some barriers require increased cooperation from government, healthcare systems, community organizations, businesses, and financial institutions to meet the needs of the clinicians and patients, which takes time, especially in a country with a developing healthcare infrastructure like Qatar.

5. Limitations of the study

The time frame for the chart review was short, from January 2019 to June 2020. The associated hospital in Sidra opened in 2016 and was officially inaugurated in 2018. The SB clinic did not start until 2018. In order to have an ample number of patients for the review, it was not possible to pull data from extended time frames given the single center review. This contributed to the limited options for longitudi-

nal analysis and small sample sizes. It is recognized that the overall sample size of this study was small compared to other registries. However, it is notable that Qatar is a small country. As Sidra is the only pediatric tertiary hospital in the nation, and with the only SB clinic, it captures the majority of children. However, not all individuals with SB in Qatar may be represented in this sample. Unfortunately, the small sample size and unknown data fields makes subcategory statistical analysis difficult. The data was collected by review of EHR notes which increased the likelihood of missed information by manual review. Access to early surgery records and birth history from outside hospitals was not available. There was no control group for comparison. There also was no data available to compare the clinic/patients prior to the formation of Qatar's SBC at Hamad Hospital or Sidra.

The GCPSB are very broad, and the purpose of this study was not to assess every component of the GCPSB but to highlight common trends from the available data. This was a limitation as not all aspects of the GCPSB were addressed. This research lends itself to further exploration and future studies. Interventions and outcomes can be further explored in future studies given the demographical framework this review provided. The newly established transition process could be assessed in future studies. Urological care can be further examined in more detail for definitions of continence, cultural influences on bowel and bladder care, and established interventions. As healthcare infrastructure continues to improve, future studies can explore if there are improvements in access to supplies, equipment, school, and community resources in the future. Although this manuscript focused generally on the GCPSB in the global context, there may be areas of clinical or statistical significance that can be further explored that can help change or improve practice patterns.

6. Conclusions

The GCPSB recommendations can be used as a framework for the care of individuals with SB in the international setting. In Qatar, concepts of the GCPSB are reflected in the knowledge and delivery of care. However, there are barriers in access to resources, healthcare infrastructure, health policy, and the community that can make implementing the GCPSB difficult. In countries with fewer resources, implementation may be even more difficult despite the applicable GCPSB recommendations. This retrospective review demonstrates alignment with many aspects of the GCPSB recommendations and global trends, as well as ongoing improvements in Qatar's SB care.

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Conflict of interest

The authors have no conflict of interest to report.

Ethical considerations

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