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Scope of Care in the First Four Years of Life for Individuals Born with Myelomeningocele: A Single Institution Experience

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Abstract

Purpose: Children with myelomeningocele are known to be consumers of substantial healthcare resources, with many early hospital encounters. The purpose of this study was to survey the extent of medical and surgical care that patients with myelomeningocele receive during the first four years of life.

Methods: Clinical and demographic data were collected on newborn infants with open myelomeningocele from the Children's of Alabama Spina Bifida Web Tracker, a prospective, comprehensive spina bifida database. Additional data pertaining to all hospital admissions, surgical procedures, and clinic visits were collected from the medical record.

Results: One hundred and fourteen subjects with a primary diagnosis of myelomeningocele between 2004 and 2015 were included. Males slightly predominated (55%), 72% were Caucasian, 11% Hispanic/Latino; 28% had a mid-lumbar functional lesion level.

Over the first four years of life, 688 total surgical procedures were performed (an average of 86 per child): 438 in year 1, 100 in year 2, 84 in year 3, and 66 in year 4. The mean number of hospital visits was 40.5. Total average drive time per patient over 4 years being 103.8 hours. Average number of nights spent in the hospital was 51.

Conclusion: Children with myelomeningocele need multiple hospitalizations, surgeries, and medical encounters in the first 4 years of life. These data will be valuable when counselling new parents and prospective parents of children with this condition.

Keywords

spina bifida; myelomeningocele; pediatrics; scope of care

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Conflict of Interest: None

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Introduction and overview:

Children born with an open myelomeningocele have a wide variety of medical and surgical needs arising from the co-morbidities of their dysraphism. Hydrocephalus is most common and requires treatment in 60-85% of cases. Other important morbidities include neurogenic bladder and bowel, lower extremity sensorimotor dysfunction and variable degrees of complex musculoskeletal disorders.[1,2]. Each requires assessment and often operative intervention or correction. Great progress has been made in the care of patients with spina bifida, but health care needs and consumption rates remain high. The associated costs and family/provider burden remain high. Parents and other providers of patients with spina bifida often comment on how frequently their child needs medical care and the extent of the early part of their child's life that is spent at the hospital. The impact of this may be overwhelming and distressing particularly because it defines a new reality for the entire family. Providing caregivers of children with spina bifida accurate information about what to expect during their child's early years of life is an important step in supporting patients and their families.

Alabi and colleagues recently reported a study of cross-sectional data from the National Spina Bifida Patient Registry (NSBPR) that addressed surgical procedures and health outcomes in 4664 patients with MMC. This report found that the most frequent procedures were neurologic and that the majority occurred in the first year. While the NSBPR provides sample sizes for evaluation, the detail and granularity of the data may be variable and less complete than an individual center may collect. The center in this study participates in the NSBPR, and this report seeks to add greater focus on the variables that most immediately impact the family experience during this time. Interest in completing this study arose from the recurring clinical observation that new families were overwhelmed by the extent to which meeting the needs of a MMC affected child impacted their time, energy and overall family dynamics. The Alabi paper establishes a compelling tally of the number of procedures, this study sought to refine the focus on the family demands. Therefore, the purpose of it is to characterize and quantify the variables during the first 4 years of life for myelomeningocele patients in a cohort of infants initially treated with post-natal closure and followed prospectively at the center over the past 4 years.

Methods

This project is a retrospective review of prospectively and retrospectively collected clinical data. A single cohort of patients was studied. Children's of Alabama (COA) is a tertiary pediatric medical center affiliated with the University of Alabama at Birmingham (UAB) that has parallel programs in pediatric (n=500) and adult/transitional (n=200) spina bifida. It follows more than 700 individuals with spinal dysraphism.

Clinical paradigms/protocols:

The program focuses on conventional post-natal closure. Following neurosurgical spinal placode closure, patients at the center are placed on an intermittent catheterization regimen to ensure that the bladder is emptying completely. During a typical 2-4 week NICU stay patients are evaluated and treated by neurosurgery, urology, orthopedics and neonatology

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teams [1,3]. An interdisciplinary clinic with care coordination is increasingly recognized as the optimal form of outpatient care[4]. During the first 5 years of life, patients are routinely seen every 3-6 months. At the time of these visits, a variety of baseline or surveillance testing is performed including urodynamics, DMSA, renal and hip ultrasounds, MRIs, CTs, x-rays and lab work. The Spina Bifida Association recommends these surveillance images and procedures as best practices in the Guidelines for the Care of People with Spina Bifida. [2]

Variables collected/surveyed:

Clinical and demographic data were collected from a prospectively maintained institutional spina bifida database and supplemented with information collected retrospectively from the electronic medical record. Institutional data are collected in a standardized fashion consistent with the data collection methods of the National Spina Bifida Program Registry (NSBPR)[5]. Inclusion criteria consisted of a primary diagnosis of open myelomeningocele, a minimum age of 4 years (birthdate between 2004 and 2015) and a requirement that all patients had received all of their elective surgical and diagnosis-specific subspecialty care at COA [6]. Exclusion criteria included primary closure elsewhere, closed dysraphism and failure to provide consent. Utilizing these criteria, 295 patients that were born between 2004 and 2015 were identified and included in the registry. Variables collected from the prospective database included age, sex, race, ethnicity, zip code, primary diagnosis, functional level of lesion, and all surgical and nonsurgical procedures. Additionally, information regarding number of hospital visits, clinic visits, and emergency room visits at Children's of Alabama were collected on all 114 patients via a retrospective chart review of the electronic medical record. Using the number of visits and patient zip codes, calculations were made to determine drive time to access care.

Research was conducted with approval from the University of Alabama at Birmingham and Children's of Alabama Institutional Review (IRB Protocol number 300001929). Patient consent was waived for retrospective data collected from the electronic medical record. Data was retrospectively collected from the institutional spina bifida database. Patients consented to be part of this institutional database. Descriptive statistics were performed using excel.

Results

One hundred and fourteen patients met inclusion criteria. Fifty-five percent were male and 61.4% were Caucasian. Thirty-eight children required an orthosis and sixty-three children required use of a wheelchair. Twenty-eight required both orthosis and wheelchair use. Additional demographic and clinical descriptors are listed in Table 1.

During the first four years of life, a total of 688 surgical procedures were performed (Table 2). Sixty-three-point seven percent of surgeries were performed in year 1, 14.5% in year 2, 12.2% in year 3, and 9.6% in year 4. A total of 5617 imaging studies were performed with the median being 39.5 and interquartile range (IQR) 31.3-52.0. Neurosurgical procedures accounted for 63% of total procedures with orthopedic, otolaryngology, general urology, skin and other following 13%, 9%, 6%, 2%, and 0%, respectively. After myelomeningocele repair, the most common neurosurgical procedures performed were ventriculoperitoneal

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shunt placement (103 procedures, 23.75%), and shunt revision (106 procedures, 24.4%). All neurosurgical procedures are listed in Table 3.

All patients underwent closure of the open spinal defect as an initial procedure. The next sequential procedure was placement of a shunt (hydrocephalus treatment). Back wound revisions (if needed) and shunt revisions (as needed) occurred later if needed at all. In addition, tethered cord release and Chiari II decompression are rare in the initial 4 years of care.

Patients who received a shunt underwent a total of 388 neurosurgical procedures and averaged 39.9 hospital visits and 2.7 emergency room visits. Twenty-three percent of patients who received ETV/CPC later required shunt placement in this cohort. Those who received endoscopic third ventriculostomy with cauterization of the choroid plexus (ETV/CPC) underwent a total of 47 neurosurgical procedures averaging 49.6 hospital visits and 3.3 emergency room visits.

Total medical encounters over a 4-year period are shown in Table 4. Patients had on average 82.1 days over the course of 4-years with at least one hospital interaction, labeled touch points. Hospital visits include outpatient clinic visits at the hospital, planned surgical, inpatient and emergency room visits. Mean number of hospital visits was 40.5. Average outpatient clinic visits was 20.4. The average number of overnight hospital stays was 51.9 and the average maximum number of consecutive days spent in the hospital was 15.3.

In year 1, there was an average of 20.0 visits per patient, year 2- 11.8 visits, year 3- 11.0 visits, and year 4- 9.0 visits. Over the first four years, there was a total of 322 emergency room visits to the treatment facility over the entire cohort. This does not include those which could have taken place at a local emergency department. Thirty-five percent of visits occurred in the first year of life (Table 4).

Average commute from residence to hospital was 1.35 hours, with total average drive time over 4 years being 103.8 hours. In this cohort 87% of patients lived 1 hour or greater from the hospital.

Discussion

Results of this single-institution study indicate that patients with myelomeningocele require a significant amount of medical and surgical care in their first four years of life. On average the typical child had 6 operations, 2.8 emergency room evaluations and 40.5 hospital visits including clinic appointment and hospital admissions.

Neurosurgical procedures made up nearly half of the procedures and were disproportionately early in the course of care. Alabi et.al and colleagues also found that the most frequent procedures for myelomeningocele patients in early life are neurosurgical.[7] The majority of neurosurgical care is comprised of myelomeningocele closure/support and hydrocephalus-related operations. Changing thresholds and preferences for hydrocephalus treatment will likely change the volume of neurosurgical care that this population needs.

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Results of this study further show that there is an evolution of care over the first four years from highly neurosurgery-centered to other surgical needs. Previous studies have shown that the rate of shunt revisions in the myelomeningocele population drops each year through the first four years of life[8]. As attempts are made to reduce the need for shunting through temporization and treatment with ETV/CPC, an important consideration is that if these measures ultimately don't work, patients are subjected to additional procedures prior to shunt placement. This increases their overall burden of care.

Although the most frequent procedures for this patient population are neurosurgical, each child requires multidisciplinary care, particularly involving urology[7,9]. Urinary tract infection (UTI) is the most common diagnosis for which spina bifida patients are seen urgently [10,11]. This is not surprising given that spina bifida is the most common cause of neurogenic bladder in children. For this reason, urodynamics studies done early in life can help identify those children at highest risk of urologic difficulties[12]. Joseph et al. found that more than half of children with spina bifida suffer from deterioration of their renal system before the age of 5 if not treated early[13]. Access to appropriate urologic care in childhood with close evaluation and follow-up in the newborn and toddler years is foundational for survival, health, social growth and high quality of life in spina bifida[13].

Newborns with spina bifida also require early and ongoing orthopedic management. Initial treatment for clubfoot repair with casting and often surgery is necessary. However, the numbers of casting and surgery insufficiently capture the burden and difficulty of this process. Treatment for clubfoot is a lengthy process requiring multiple follow-up visits, ongoing therapy, and multiple casting appointments. Long term assessment of hip dysplasia and scoliosis are also needed. Orthotic support and ambulatory assistive devices are typically required to promote early independence and functional development. Proper fit and function of these devices is essential to optimize ambulation and minimize complications such as pressure sores and ulcerations. This requires ongoing serial moldings, fittings and adjustments which is typically performed by orthotists under the direction of Physical Medicine and Rehabilitation physicians.

The extensive needs that impact multiple domains of care underscore the need for regular multidisciplinary follow up, education and support for spina bifida patients and their families. In this context, the multi-disciplinary clinic is important in providing centralized support, experience and expertise in an environment that fosters communication and multidisciplinary interaction and planning. Also, this environment also can promote efficiency of care. Complex care plans are developed in the context of multiple system illness and support/need from various services. Patients are able to see a number of subspecialists during a single clinic visit. This saves time and resources that may be associated with multiple journeys and appointments. If patients at the institution did not have the opportunity to participate in a multidisciplinary clinic, the costs to see the same providers would be significant. In the first year of life, patients visit the multidisciplinary clinic four times and see four providers each visit, which would result in 16 separate visits in the absence of a multidisciplinary clinic. For the second year of life, patients make two visits to the multidisciplinary clinic and see 4 providers, which would result in 8 separate visits. For the third year of life, they have 2 visits to the clinic and see 5 providers,

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resulting in 10 separate visits. For the fourth year of life, they have 2 clinic visits and see 6 providers, resulting in 12 separate visits. Over the first four years of life, this would result in a difference of 36 clinic visits in the absence of a multidisciplinary clinic (46 without multidisciplinary clinic; 10 with multidisciplinary clinic). These visits are in addition to the emergency room appointments and post-operative follow-up visits. As such, each clinic visit requires a significant investment of time, energy and resources for each family. Yet, it is likely that the overall burden of care would be substantially higher in the absence of a multidisciplinary clinic.

Caring for a child with spina bifida and addressing the many complexities of medical treatment for this population is inherently stressful[14]. Medical and support needs are continuous, omnipresent and acute needs occur unpredictably. The psychological and physical burden of this upon patients and families is considerable and not completely understood. Nevertheless, the information that is provided is cited as a critical resource in medical decision-making for caregivers of this patient population[15]. Previously published studies have demonstrated a complex interplay of individual, family, socio-economic and demographic factors that interact to impact quality of life in parent-providers[17]. Having a child with spina bifida did not predict depression in parents, however, quality of life was adversely impacted[17]. The largest meta-analysis of studies published related to psychological health in parents of children with SB showed a high level of stress[18]. Key determinants of success included partner relationship quality, the family climate and the support of informal social networks [18].

Results of this study could potentially provide information to caregivers of children with myelomeningocele with regard to typical expectations during their child's first four years of life. Major strengths of this study include a large cohort of patients with myelomeningocele that had received all of their spina bifida medical care at the institution from birth to four years of life, and that the institution has a robust multidisciplinary spina bifida clinic.

This study has several limitations. First, the data is purely observational and does not survey any component of family response to these visits. There is likely considerable variation regarding burden to the family among different types of visits which is not captured in this data. Secondly, this study was conducted at a single institution in the Southeastern United States. Third, it does not quantify the cost of care that patients with myelomeningocele receive during the first four years of life. Fourth, this study did not measure nor address the considerable psychological burden of these care needs upon patients or families. Finally, it only included patients that had received all their medical care during their first four years of life at the institution and excluded any patients that had received treatment at another institution prior to moving their care to the treatment center. Following these patients throughout early adolescence will provide a more comprehensive and accurate picture of how their care evolves as well as the burden of care. Future research and reporting will be valuable as the patient ages to continue to quantify the disease burden for patients with spina bifida. It is suspected that their neurosurgical needs will decline, and the needs related to urologic management, wound care, and equipment/surgical intervention to maintain ambulation will evolve and remain at the forefront of their care. Another area for future

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research could be in sub stratifying the burden of care based on lesion level, presence of hydrocephalus, and other spinal dysraphisms.

Conclusion

Children with myelomeningocele undergo multiple hospitalizations, surgical procedures, and medical encounters during their first four years of life. Neurosurgical procedures are the most common early on, but dissipate with time. Acute needs for support of hydrocephalus continue but predictable needs evolve to include more urologic and orthopedic interventions along with psychosocial support. This data can be utilized when counseling new parents and prospective parents of children with myelomeningocele.

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Table 1.

Demographics

Parameter	n (%)
Patient demographics (n=114)	
Male	63 (55.3)
Female	51 (44.7)
African Americans	27 (23.7)
Caucasian	70 (61.4)
Hispanic	12 (10.5)
Other/unknown	5 (4.4)
Primary diagnosis	
Open myelomeningocele	114 (100)
Functional level of lesion	
Thoracic	13 (11.4)
High-lumbar	13 (11.4)
Mid-lumbar	32 (28.1)
Low-lumbar	20 (17.5)
Sacral	36 (31.6)
Ambulation	
Community	53 (46.5)
Therapeutic	0
Household	7 (6.1)
Non	54 (47.4)
Bracing orthosis	
Ankle foot	32 (28.1)
Supra-malleolar	4 (3.5)
Reciprocating gait	1 (0.9)
Knee ankle foot	1 (0.9)
Wheeled mobility device	
Self propelled	56 (49.1)
Attendant only propelled	3 (2.6)
Sports wheelchair	3 (2.6)
Self propelled with power assist	1 (0.9)
Insurance plan	
Primary	114 (100)
Commercial PPO	43 (37.7)
Commercial HMO	2 (1.8)
Medicaid	69 (60.5)
Secondary	63 (55.3)
Medicaid	20 (17.5)
State high risk plan	42 (36.8)
Tricare/other military	1 (0.9)

Parameter	n (%)
Tertiary	12 (10.5)
State high risk plan	12 (10.5)

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Table 2.

Surgical Procedures and Imaging

	Year of life								Total (%)		mean	median	IQR
	1		2		3		4						
Procedures	438	(63.7)	100	(14.5)	84	(12.2)	66	(9.6)	688	(100.0)	6.0	5.0	(3.0-7.0)
Neurosurgery	332	(76.3)	42	(9.7)	26	(6.0)	35	(8.0)	435	(63.0)	3.8	3.0	(2.0-4.8)
Orthopedic	28	(32.2)	21	(24.1)	23	(26.4)	15	(17.2)	87	(13.0)	0.8	0.0	(0.0-1.0)
Otolaryngology	22	(33.8)	13	(20.0)	18	(27.7)	12	(18.5)	65	(9.0)	0.6	0.0	(0.0-0.8)
General	28	(63.6)	7	(15.9)	7	(15.9)	2	(4.5)	44	(6.0)	0.4	0.0	(0.0-0.0)
Urology	18	(42.9)	15	(35.7)	7	(16.7)	2	(4.8)	42	(6.0)	0.4	0.0	(0.0-1.0)
Skin	10	(83.3)	0	(0.0)	2	(16.7)	0	(0.0)	12	(2.0)	0.1	0.0	(0.0-0.0)
Other procedure/ study	0	(0.0)	2	(66.7)	1	(33.3)	0	(0.0)	3	(0.0)	0.0	0.0	(0.0-0.0)
Imaging	2911	(51.8)	1096	(19.5)	812	(14.5)	798	(14.2)	5617	(100.0)	49.3	39.5	(31.3-52.0)

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Table 3.

Total Neurosurgery Procedures

Neurosurgical Procedure	Year of life				Total (%)
	1	2	3	4	
Myelomeningocele repair	114	0	0	0	114 (26.2)
Shunt revision	46	28	17	15	106 (24.4)
Shunt placement v-peritoneal	93	5	2	3	103 (23.7)
Shunt placement EVD (external ventricular drain or ventriculostomy)	19	3	2	6	30 (6.9)
Endoscopic third ventriculostomy (ETV)	22	0	0	0	22 (5.1)
Shunt removal	7	1	2	3	13 (3.0)
Shunt replacement	6	2	0	3	11 (2.5)
Tethered cord release	7	0	2	1	10 (2.3)
Chiari decompression	8	0	0	1	9 (2.1)
Removal of external subdural drain	5	0	1	1	7 (1.6)
Revision of myelomeningocele repair	2	1	0	0	3 (0.7)
Shunt placement subgaleal	2	0	0	0	2 (0.5)
Shunt placement v-atrial	1	0	0	1	2 (0.5)
Syringomyelia shunt placement	0	1	0	1	2 (0.5)
Craniotomy	0	1	0	0	1 (0.2)
Total (%)	332 (76.3)	42 (9.7)	26 (6.0)	35 (8.0)	435 (100.0)

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Table 4.

Medical encounters over a 4-year period with drive time

	Mean	Median	IQR
Hospital touch points	82.1	55.0	(38.0-80.8)
All hospital visits	40.5	33.5	(25.3-53.0)
Outpatient clinic visits	20.4	20.0	(14.0-26.8)
Emergency department visits	2.8	1.0	(0.0-3.0)
Drive time (hrs)	103.8	87.6	(51.8-138.3)
Nights spent in hospital	51.9	31.0	(19.3-55.3)
Maximum consecutive days in hospital	15.3	9.0	(6.0-13.0)