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## Philosophy of care delivery for spina bifida

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### Abstract

The multidisciplinary model (MCM) is described as one that utilizes skills and experience from practitioners belonging to various disciplines, each treating patients from a specific clinical perspective.<sup>1</sup> The Spina Bifida Association (SBA) supports and recommends that clinical care for people with Spina Bifida (SB) be provided in specialty clinics of which the MCM is an example; that care be coordinated; and that there be a plan for transitional care.<sup>2</sup> This paper explores the challenges the MCM faces with a transitioning and aging population in a care system that calls for a positive patient experience, engaged health care professionals, desired outcomes, with consideration of cost.

### Keywords

multidisciplinary care model; Spina bifida; Cost and outcomes

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Declaration of competing interest

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## Introduction

Spina Bifida is a congenital, complex, costly, lifelong condition that requires the attention of multiple healthcare specialties. A majority of individuals with SB require treatment and ongoing management of hydrocephalus, bowel and bladder incontinence, and insensate skin.<sup>2</sup> Babies born with SB are now expected to live into adulthood<sup>3</sup> and the population of those living with SB in the US today includes more adults than children.<sup>4</sup> However, medical care for adults with SB is not readily available in many regions of the country.

The complexity of SB, the front loaded and life-long high cost of care,<sup>5</sup> and the scarcity of care beyond that provided in the pediatric setting, warrants attention be paid to how care is delivered and managed, the results of the care provided, and a plan for preparation and execution of transition to the adult system of care. For children with SB to benefit maximally from the many aspects of care delivered, and to progress successfully into adulthood in a developmentally appropriate way, care must be planned and coordinated in collaboration with the family and the medical home, the healthcare providers, the school system, and other systems with which they may interact.<sup>6</sup> And, as most people born with SB will move into the adult care system, planning for transition must be intentional in the pediatric setting and the transfer coordinated with adult providers.

The clinical model most often used to provide care to individuals with SB—the MCM—focuses on the involvement of multiple healthcare provider specialties seeing patients in the same clinical space on the same day.<sup>1</sup> In the 1940s and 1950s, when the prevalence of polio began to decrease, some of the MCM clinics funded by March of Dimes were converted to care for children affected by SB using this same model. Over time, and to better meet the needs of individuals living with SB, clinics added urologists and neurosurgeons to the existing care team that already included orthopedists, neurologists and physical therapists. During the 1970s and 1980s, multidisciplinary clinics that provided outpatient care for children with SB had been established in almost every state in the US.<sup>2</sup> As if by default, and without evidence of clinical effectiveness, this model has been adopted for the care of children with SB though implementation of the model may not include processes that are key to the effective delivery of complex care across the lifespan.

Today there are 104 multidisciplinary SB Clinics in the US. Some of these clinics participate in the National Spina Bifida Patient Registry (NSBPR), a clinic-based longitudinal registry of patients with SB sponsored by the Centers for Disease Control and Prevention. Most of these clinics utilize the MCM that includes a urologist, social worker, nurse practitioner/nurse coordinator, and physical therapist who are present in the clinic. Some also have a neurosurgeon, orthopedist, orthotist, nutritionist, pediatrician, and physiatrist internal to the clinic. Clinic frequency, the number of patients seen, and how disciplines are involved differ among the participating clinics.<sup>7</sup> Interventions and outcomes reported in the NSBPR vary among the clinics,<sup>8</sup> and include data not previously reported until the initial Registry data were analyzed.

It is the goal of the SBA to reduce the variability in care provided and resulting outcomes in SB clinics and to promote the inclusion of care processes recommended to improve

outcomes for this costly, chronic, complex condition. Cystic fibrosis (CF) and hemophilia are examples of conditions that are complex and lifelong whose clinics have relationship with agencies dedicated to improve care outcomes. These relationships require the inclusion of certain processes of care and the measurement of clinically important outcomes. CF clinics have had a strong relationship with the Cystic Fibrosis Foundation (CFF) for more than 50 years, which has resulted in a care delivery system that is defined and specific clinical outcomes measured, such as body mass index and lung function.<sup>9,10</sup> Hemophilia Treatment Centers (HTC) also operate with specific goals which are prescribed by the Health Resources and Services Administration (HRSA) that speak to the need for community based coordinated care. HTC's partnership with healthcare professionals, government agencies, and consumers has resulted in optimized care, improved health outcomes, education, linkages to needed medical services, and community outreach to other services needed by the patient to realize optimum outcomes.<sup>11</sup>

### **Coordination of Spina Bifida care and with a medical home**

SBA identified coordination of SB specific care with care provided in the medical home as a key process to be included in the delivery of SB care.<sup>12</sup> Practices recognized as medical homes by the National Committee on Quality Assurance (NCQA) demonstrate patient-centered care and clinical quality through “streamlined referral processes and care coordination with referring clinicians, timely patient and caregiver-focused care management, and continuous clinical quality improvement”.<sup>13</sup> In 2007, the American Academy of Pediatrics (AAP), the American Academy of Family Physicians, the American College of Physicians, and the American Osteopathic Association authored the Joint Principles of the Patient-Centered Medical Home to promote an approach to comprehensive primary care for children, youth and adults that facilitates partnerships between patients, families, and their physicians.<sup>14</sup> Core medical home principles include a personal physician, a whole-person orientation, and care that is coordinated and/or integrated. The AAP further defines the medical home as one that provides care that is “accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally effective”.<sup>14</sup>

Care coordination may be based in the SB Clinic or in the medical home. This function must be clearly delineated between the SB clinic and the primary care physician for care to be coordinated effectively. Calado and Loff found in their SB clinic that a single person providing care coordination with patients in their communities and the local primary care provider helped to identify patients at risk for preventable conditions. This local collaboration resulted in timely referral to appropriate providers when risks for complications were identified, reducing the burden for the patient and the family and the unnecessary cost to the health care system.<sup>15</sup>

Care coordination links children and their families to services and resources that may be needed to optimize outcomes, that have been expressed in a patient-centered care plan, and that may address the social, developmental, educational, and financial needs of the patient and family.<sup>16</sup> The lack of reimbursement for the professional time spent conducting care coordination activities and the challenges in measuring the benefits of these activities, such as avoidance of emergency department visits and hospitalizations, are barriers in today's

healthcare system and make this a more challenging process to implement. Any effort at care coordination must take into account the shifting demographics within the pediatric population across the nation and the unique challenges this presents. For example, within the NSBPR, Hispanics comprise a larger proportion within the younger age groups (See Table 1). Therefore, as the current SB population ages, it will become critical to assess racially/ethnically salient issues and design culturally appropriate care/service coordination.<sup>17</sup>

A systematic approach to provide care coordination for children with complex childhood onset conditions is central to an effective and efficient care model.<sup>16</sup> SBA's mission – to enhance the lives of people with Spina Bifida – will be best supported through its collaborative work with SB clinics to identify models of effective care coordination; participate in the development of consensus standards for care coordination services; and provide education to the professionals involved in this essential component of care.<sup>16</sup>

Given the complex nature of SB, the comprehensive services offered in SB clinics, and the expertise of the providers, children with SB often obtain all or most care from the SB MCM and consider the SB clinic to be the source of all their medical care. As stated earlier in this paper, a clear distinction must be established with the patient and family so that both the necessary specialty and primary care are provided, either in the SB clinic or in collaboration with the primary care provider. Because the MCM is rare for adults with SB, their care is usually provided by a primary care provider. Patients and parents must be prepared in the pediatric setting for the changes that result from this shift in care provision from a specialty focus to an adult primary care focus. This is an important aspect of the preparation for transition that should occur in the pediatric SB clinic.<sup>6</sup>

Another example of a care delivery model for a complex, chronic condition such as SB, is a “patient-centered specialty practice”.<sup>18</sup> Examples of this care model already exist within oncology, physiatry (Physical Medicine and Rehabilitation or PM&R), and cardiology.<sup>18</sup> The care team works with one or more primary care providers and may collaborate with other specialists outside the clinic on a consultative basis. Another model may embed additional specialists with expertise in a particular condition into the specialty-based medical home to provide access to a broader range of providers. Family practice, medicine-pediatrics (med/peds), and PM&R physicians can be especially effective in providing medical homes for adults with SB given their breadth of experience in providing comprehensive care for pediatric and adult patients. One example of a patient centered specialty practice is PM&R for adults with SB at the University of Pittsburgh Medical Center (UPMC) Adult Spina Bifida Clinic. This adult clinic is led by a physiatrist who oversees a team comprised of a physician assistant, nurse, dietitian, personal trainer, peer counselor, and orthotist. The adult clinic is located adjacent to the adult urology clinic and same-day scheduling for appointments and testing are available. Referrals are made to other subspecialties as need indicates.

## Transition

The primary goal of transition as outlined in the “Guidelines for the Care of People with Spina Bifida” is to maximize lifelong functioning through the provision of quality,

developmentally-appropriate healthcare that is uninterrupted from adolescence to adulthood.<sup>19,20</sup> (see Table 2) The Transition Guideline delineates key elements for a successful transition program: coordination of transition to adult oriented care; flexibility regarding timing of transition based on attributes of the individual such as development and health status; and beginning transition activities at 12–14 years of age, including the development of a medical summary, exploration of insurance issues, and the identification of adult care providers.<sup>12</sup> For transition from the pediatric to the adult system of care to occur effectively, planning must be family-centered and coordinated. This may occur in the medical home with primary care or, for youth with chronic complex conditions, in sub-specialty clinics.<sup>6</sup>

Preparing individuals with SB for independent self-management when care is transferred to the adult health care system has not been a universally recognized or a defined practice in SB pediatric clinics. Its importance is now being driven by the developing awareness that SB is no longer only a pediatric condition. When pediatric SB MCM clinics do attempt to transition patients as they approach adulthood, there is a dearth of subspecialists available to provide the necessary care, and primary care practices may lack the resources for care management of this population.<sup>6</sup> This results in a prevalent lack of care coordination, inadequate communication among care providers and with families, crisis driven management, and inadequate support of family caregivers<sup>6</sup> As a result, the health care of adolescents and young adults with SB is often substandard. The early and costly investment in comprehensive care for individuals within the pediatric setting may be jeopardized by this lack of appropriate care in the adult-centered care system.

There are models of care today that address preparation for and execution of the transition of SB care like that at Baylor College of Medicine and the UPMC Adult SB clinic. Collaboration between the pediatric SB MCM clinic and a med/peds physician-directed transition clinic at Baylor College of Medicine in Houston, Texas is an example of a successful strategy. This transition clinic provides medical care and social support services to adolescents and young adults with various chronic childhood illnesses or disabilities as they move from pediatric to adult healthcare. The SB transition team within this clinic begins seeing patients at 14 years of age in the pediatric clinic setting. They address SB chronic condition management, adolescent health concerns, and aid in setting appropriate adult health expectations. At age 19, the patient's care is transferred to the same Transition Medicine Clinic team, with delivery now within an adult-centered location.<sup>21</sup> At UPMC, the transition model is PM&R based. The pediatric SB clinic utilizes a traditional MCM model and is housed within PM&R. Psychiatrists lead the multidisciplinary team of pediatric providers. A physician assistant sees patients in both clinics and serves as a bridge between the pediatric and adult SB clinics, facilitating transition.

## Discussion

The medical care of people with SB is complex, costly, and lifelong. Today, the SBA recommends that care for individuals living with SB be provided in a specialty clinic that includes a physician and a nurse with access to the many specialists needed to address this complex condition. The MCM is one example of a specialty clinic model that is often used to provide care for people with SB. Other than the involvement of multiple specialists, care

processes of importance, such as care coordination and transition preparation and execution, are not inherently part of this model and may or may not be provided. Specialty clinics that include these processes may effectively support populations with complex conditions to realize positive and desired health outcomes. More research is needed to determine which specialties and processes actually impact individuals in ways that support the intensity of resources thought to be needed.<sup>22</sup>

To that point, a particular and unique challenge for SB clinics is their reliance on the participation of procedure-based specialists. Indeed, the first notable interaction between an individual with SB and their health care providers is with a surgical team closing the SB defect (and potentially placing a ventricular shunt). Across their lifespan, people with SB will require care provided by procedure-based specialties such as neurosurgeons, orthopedists, and urologists. These procedure-based specialists are often under significant pressure to perform high-revenue procedures rather than to provide complex, well-coordinated, and often less-well-reimbursed clinical care, which is the type of care that people with SB require.<sup>23</sup> Surgeons may experience financial losses from their participation in such coordinated care delivery models.<sup>24</sup> Academic medical centers previously benefitted from multi-disciplinary, complex care clinics. However, it is unclear to what extent these trends will apply in an era of ever-changing health care reform. Further studies are needed to determine how to most efficiently and effectively engage providers from a broad array of backgrounds and who answer to a broad array of financial requirements and incentives in order to provide the highest quality care to people with SB.

Within SB clinics, practices that affect outcomes, how and which health care professionals are involved, and the desired characteristics of multidisciplinary care have not been clearly established and have not been regulated or influenced by any single agency or organization. As a result, different standards and models of care exist.<sup>25</sup> The 2018 “Guidelines for the Care of People with Spina Bifida” promote the elements thought to be necessary for best care delivery and include specific care processes for clinics serving people with SB: care coordination and transition preparation and execution.<sup>19,20</sup> (See Table 2) And, beginning in 2020, SB clinics that successfully demonstrate the inclusion of these practices may be designated an SBA Clinic Partner, beginning a relationship with the only US agency whose focus is to improve the lives of people living with SB.

Recognizing the challenges of establishing and maintaining a SB clinic with access to the many needed specialists, as well as consideration of the costs to the healthcare system to provide care to individuals with this complex condition, there is demand for the systematic assessment and evaluation of how clinical care is implemented and what is needed to do so effectively and efficiently. The development of alternative models led by family practice, psychiatry, internal med-peds, or developmental pediatrics providers that incorporate care coordination, transfer of care preparation and execution, may provide effective management and care of patients with complex rare conditions across the lifespan.<sup>26</sup> Under the leadership of SBA in partnership with SB clinics, exploration of other care models may lead to a better understanding of how patients with rare conditions and their families could be served more effectively and efficiently by specific services and systems of care.



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**Table 1**

Age and race/ethnicity, 2009–2018.

<b>NSBPR Age and Race/Ethnicity, 2009–2018</b>		
<b>Age at Last Visit</b>	<b>Frequency</b>	<b>Percent</b>
Younger than 2	770	8.07
2 to <5	1232	12.91
5 to <10	2040	21.37
10 to <13	1127	11.81
13 to <18	1831	19.18
18 to <22	1035	10.84
22 or older	1510	15.82
<b>Total</b>	<b>9545</b>	

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**Table 2**

Guidelines for the care of people with spina bifida – topical areas.

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<b>System of Care</b>
<ul style="list-style-type: none"> <li>• Care Coordination</li> <li>• Health Promotion and Preventive Health Care Services</li> <li>• Prenatal Counseling</li> <li>• Transition</li> </ul>
<b>Psychosocial Context for Self-Management</b>
<ul style="list-style-type: none"> <li>• Family Functioning</li> <li>• Mental Health</li> <li>• Self-Management and Independence</li> <li>• Quality of Life</li> </ul>
<b>Neuropsychology and Neurosurgery</b>
<ul style="list-style-type: none"> <li>• Neuropsychology</li> <li>• Neurosurgery</li> </ul>
<b>Mobility, Orthopedics, and Physical Activity</b>
<ul style="list-style-type: none"> <li>• Mobility</li> <li>• Orthopedics</li> <li>• Physical Activity</li> </ul>
<b>Urology and Sexual Health</b>
<ul style="list-style-type: none"> <li>• Men's Health</li> <li>• Sexual Health and Education</li> <li>• Urology</li> <li>• Women's Health</li> </ul>
<b>Specific Health Issues</b>
<ul style="list-style-type: none"> <li>• Bowel Function and Care</li> <li>• Endocrine: Puberty and Precocious Puberty</li> <li>• Endocrine and the Use of Human Growth Hormone</li> <li>• Integument (Skin)</li> <li>• Latex and Latex Allergy in Spina Bifida</li> <li>• Nutrition, Metabolic Syndrome, and Obesity</li> <li>• Sleep-Related Breathing Disorders</li> </ul>

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<https://www.spinabifidaassociation.org/resource/guidelines/>.