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Primary care providers and medical homes for individuals with spina bifida

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Abstract. The contributions of primary care providers to the successful care of children with spina bifida cannot be underestimated. Overcoming systemic barriers to their integration into a comprehensive care system is essential. By providing routine and disability specific care through the structure of a Medical Home, they are often the first line resource and support for individuals and their families. The Medical Home model encourages primary care providers to facilitate discussions on topics as varied as education and employment. Knowledge of specific medical issues unique to this population allows the primary care provider to complement the efforts of other specialty clinics and providers in often neglected areas such as sexual health, obesity and latex sensitization. As individuals with spina bifida live into adulthood, and access to traditional multidisciplinary care models evolves, these skills will take on increasing importance within the scope of providing comprehensive and coordinated care.

Keywords: Spina bifida, medical home, children with special health care needs, disability

1. Introduction

The multidisciplinary care model is often the "norm" and certainly the "ideal" for children and young adults with spina bifida. This model, long advocated by the Spina Bifida Association as the optimal method to provide care to individuals with spina bifida, at its best effectively involves and integrates an identified primary care provider (PCP) into the long term care and management plans. What aspects of this care delivery model make it successful? What are the barriers that limit a PCP's participation? Can the primary care physician's role be better delineated and expanded as this patient population grows older, their health needs grow more complex and their access to multidisciplinary care declines?

Spina bifida is a unique disorder; there are ongoing needs for surgically and medically based expertise across the lifespan. Adult survival rates now approach 85–90% [10]. The interventions of the past 60 years (e.g., reliable ventricular shunt devices, clean intermittent catheterization techniques, etc.) and their effect on longevity have required providers to better observe and address the natural history of this disorder and its effects over time, not unlike the experiences with adult survivors of infantile polio (post-polio syndrome). Interventions that are essential and often life saving when originally performed are now known to impact future morbidity and mortality [10].

2. The medical home

Arguments supporting a Medical Home for individuals with special health care needs have no age limit. A March 2007 consensus statement by the American Academy of Family Physicians, the American Academy of Pediatrics, the American College of Physicians, and the American Osteopathic Association defined the principles of the patient centered medical home (PCMH) [1]. (Available at www.medicalhomeinfo.org).

Similar principles have also been proposed in Healthy People 2010 and through the efforts of the Maternal Child Health Bureau.

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1. Families of children and youth with special health care needs (CYSHCN) are partners in decision making and are satisfied with the services they receive.
2. CYSHCN receive ongoing comprehensive care within a Medical Home (MH).
3. Families of CYSHCN have adequate private and/or public insurance to pay for the services they need.
4. Children are screened early and continuously for special health care needs.
5. Community based services for CYSHCN are organized so families can use them easily.
6. Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life including adult health care, work, and independence.

A recent literature review of the benefit of CYSHCN receiving comprehensive care within a medical home demonstrated moderate support for each of these Maternal Child Health Bureau recommendations [14]. Specific positive outcomes for children identifying a Medical Home have been described. They are one-half as likely to experience delayed or forgone care. They are less than one-half as likely to have unmet health care needs. They are less than one third as likely to have unmet needs for family support services [29].

Managing only health is no longer enough. Promoting health and improving quality of life are essential as well [5]. The Institute of Medicine's framework to assess quality of care requires consideration of patient safety, effectiveness, efficiency, family-centered care, timeliness, and equity [27]. The key components of quality care, beyond the inherent medical expertise, are championed through the Medical Home concept: care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, culturally effective and for which the Primary Care Physician shares responsibility.

Of these, the commitment to care coordination, the "process that links children and youth with special health care needs (CYSHCN) and their families with appropriate services and resources in a coordinated effort to achieve good health," characterizes the successful multidisciplinary clinic. Identified barriers to care coordination exist across practice settings and regardless of patient age: adequate reimbursement, role definition for the various participants, system limitations, a lack of medical and community knowledge and ineffective communication among providers. Proposals to improve care coordination have included developing registries, adapting information technology strategies, and promoting health information exchange methods. Unfortunately, current studies have identified neither the specific care coordination strategies most likely to be useful in any given practice setting nor the amount of time and work needed to provide quality care coordination services [12]. What is known from the single study that evaluated the elimination of a spina bifida multidisciplinary clinic is that the subsequent absence of a single person assuming the role of care coordinator was directly related to poorer outcomes in those spina bifida patients [16]. For individuals with spina bifida, especially adults, it is within this construct of a Medical Home where the role of the primary care provider must be nurtured and supported.

The care provided through a Medical Home must be "family centered." To do this, a PCP's commitment of time and a willingness to listen to family concerns is essential. Primary care providers may play important roles by sharing family values and customs with subspecialty providers. They may serve as an effective conduit for new evidence based medical information to be shared with the family. The PCP may also be a valuable resource to monitor and report on the effects of interventions implemented by the specialists [29]. Families and patients may also be integrated into practice based quality improvement activities. By supporting and partnering with families in their role as caregivers, additional local resources and patient specific insights may come into play to help optimize approaches to an individual's health.

A major responsibility of the primary care/Medical Home provider is to support individuals with spina bifida in all aspects of their life, to recognize their individual abilities and to assist in their successful integration into society. A poor adaptation and transition places affected individuals at risk for ongoing problems in adulthood: underemployment, unemployment, limited independence, poor self-esteem, and reliance on federal and state support programs [13].

2.1. Education

Recognizing and addressing specific educational concerns are an important part of this support process. The core cognitive deficits of spina bifida emerge in infancy, persist throughout life, and are present regardless of cognitive ability. Executive dysfunction, the ability to monitor and regulate goal directed behaviors, is most frequently described in the neuropsychological literature and becomes progressively more problemat-

ic in adolescence and early adulthood because of the increased need for independent problem solving [3,13].

Studies trying to predict eventual outcome and identify factors have produced variable results. The presence of shunted hydrocephalus and subsequent shunt revisions are associated with poorer outcome. For a child with hydrocephalus and a lesion level above L3, the need for special education support approaches 60% [3]. In children without hydrocephalus, the proportion of those in primary level special education (17%) is higher than that of the general population (5%); however, by the end of secondary education the proportion is similar (8%) [3]. For a child without hydrocephalus and a lesion level of S1 or lower, the typical need for extensive special education services is similar to the general population.

2.2. Employment

Employment has been associated with better quality of life in many chronic conditions. It provides financial independence and provides an additional environment for social interaction and a sense of self-esteem. Having a job is an important aspect of societal integration.

Studies focusing on work participation by individuals with spina bifida showed overall employment rates varying between 19 and 38%. In one, the level of education was the only significant general predictor of work participation [30]. This is not surprising as the requirements for a successful educational career resemble those for success in the labor market. This finding supports efforts by everyone with spina bifida to pursue the highest level of education their ability allows. Reported problems with obtaining employment included being offered work that was physically or mentally too demanding, transportation facilities, accessibility of buildings and toilet space. However, the most commonly reported problem was a reluctant attitude among employers [30].

Significant determinants of having paid work for at least 1 hour a week were: level of education, level of lesion, hydrocephalus, cognition, functional independence, and ambulation. Significant determinants of full-time employment were the same, along with type of spina bifida and male sex. The difference in work participation between the sexes appears to be higher in spina bifida patients [30]. Other studies have shown that employment is associated with better general health, vitality and overall satisfaction with life and inversely associated with bodily pain. One could argue that adequate management of bodily pain and vocational rehabilitation may further optimize functional status and quality of life in these patients.

3. Cost and access

The issue of medical care cost is a significant one for any individual with a chronic care need; it is even more of an issue for individuals with spina bifida than similar patient groups. Ouyang et al studied private insurance medical expenditures of children and adults with spina bifida, comparing them to average/typical medical expenditures in other patient groups [26]. Adults with spina bifida had average medical expenditures three to six times greater than adults without spina bifida. Children ages 1–17 years with spina bifida had average medical expenditures 13 times greater than children without spina bifida [26]. This cost ratio is dramatically different from Newacheck's analysis of the 2000 Medical Expenditure Panel Survey [25]. He showed that children with special health care needs on average incurred medical expenditure three times higher than other children. Children with spina bifida incur higher than average medical care utilization and expenditures even among children with special health care needs [26].

The costs associated with care coordination and the lack of reimbursement for this important primary care provider (PCP) activity further complicates appropriate access to care and the cost of that care. Funding agencies must recognize the value of work that occurs outside the limits of the face-to-face visit. PCP coordination includes work within the practice, between consultants, with ancillary providers and with community resources. Rewarding PCPs whose coordination efforts and proactive care decrease hospitalization costs and those with a difficult case mix would further encourage adaptation of Medical Home principles.

Adult access to multidisciplinary spina bifida clinics varies tremendously across this country and is more often the exception rather than the rule. These clinics as they currently exist, however, cannot be the long term solution for this population. Service models will need to evolve if we are to continue successfully providing care for adults with spina bifida. Several factors may drive this evolution:

1. Most multidisciplinary clinics are located or coordinated through pediatric facilities. Individuals born with spina bifida are living longer. As they age, access to care and to appropriate specialty providers familiar with spina bifida may no longer be available through these programs because of funding mechanisms and institutional policies.

2. The "typical" diseases of adulthood and age not specifically associated with spina bifida are not "pediatric" and may be unfamiliar to pediatric providers. Should we expect individuals with spina bifida to choose between areas of health care expertise: special health care needs vs. typical health care needs?
3. Life tasks and decisions (e.g., where to go to college, where to live, etc.) should not be dominated by health care considerations. Will the physical location of established multidisciplinary clinics limit where individuals can and cannot live as adults if they are the only available source of appropriate care?

In each of these areas (age, expertise, location), the process of integrating primary care providers and families into current care models and, subsequently, taking advantage of their strengths should begin early in life. Kinsman et al proposed a care model that places less emphasis on how team members structure their interactions with each other, with patients and with their families: multidisciplinary, interdisciplinary, transdisciplinary [18,23]. Instead they emphasized the functional, rehabilitative and participatory perspectives of the World Health Organization's ICIDH-2 (International Classification of Function, Disability and Health) model. This model better characterizes a lifespan approach: comprehensive, coordinated, and longitudinal. It also better considers the areas of body function/structure, activities, participation and environment and how these affect health and quality of life. An integral part of this care is anticipatory guidance and effective transitional planning throughout the clinical relationship. Just because someone has special health care needs, it does not mean that they do not have other typical and preventive health care needs.

It is the continuing responsibility of primary care providers to address issues that are important to their patients, regardless of their ability or disability. One could argue that a primary responsibility of the pediatric multidisciplinary care team is to develop care coordination and self management skills in the children, families and primary care providers throughout the care relationship and to educate and integrate adult providers into an appropriate service delivery method during the transition process. One successfully transition model to adult care has been to "share" care responsibilities between the pediatric team and the adult care provider for a specific period of time.

While there may be pediatric specialists with the ability to consolidate all of the information and opinions and recommendations together and to resolve conflicting advice, this is rarely the case in an adult specialty health care system. The need for an identified primary care role takes on even greater importance as individuals age.

4. An approach to care

4.1. Routine care

Several resources identify preventive and ongoing care needs for individuals with spina bifida at different ages. These address the various body systems and the potential interventions that may be required. An excellent example, Guidelines for Spina Bifida Health Care Services Throughout the Lifespan, is available through the Spina Bifida Association [22].

Most philosophical aspects of providing primary care to individuals with spina bifida parallel those of the Medical Home. There are, however, additional considerations that are extremely important to being a successful primary care provider for this population.

1. Think transition: Transition begins at birth utilizing a series of developmentally appropriate interventions and does not stop. It is a process, not an event, and is individually centered. There will always be some aspect of the health, education, social and community systems that is changing. Anticipate future needs and the need for flexibility. Work with the family to consider all options when change is coming. Incorporate the developmental steps of typical development.
2. Identify ability: Parents are all too familiar with the things their child cannot do; reciting that list rarely adds anything to the interaction. Is a skill absent because of a lack of ability or opportunity? Children need the opportunity to try, to succeed and sometimes to try again. Support parents in this difficult process.
3. Foster independence: Self-care is a critical series of necessary tasks. Define specific parts of a task, however simple, that can be done by the individual themselves. Encourage parents to recognize the incremental, successful steps; do not wait for the final finished product. They will miss so much along the way!
4. Teach advocacy: While the parents may be a child's first advocate, be sure that there are opportunities for the child to express their opinion both at home and in the office.

4.2. Emergency preparedness

Children with spina bifida have specific health needs that do not go away during times of emergency. Preparation, however, means more than just having additional supplies on hand. Primary care providers must insure that their patients' families have the necessary information and documents available and accessible. Experiences following Hurricane Katrina have shown that children, their families and their medical information do not always move together. There are several formats available to help organize this information, including one available through the American Academy of Pediatrics (http://www.medicalhomeinfo.org/tools/emer_med.html).

5. Things no one else remembers

Despite the number and diversity of health care providers typically involved with children having spina bifida, there always seem to be some issues and topics that don't quite "fit" within one particular specialty. The presumption is that someone else is taking care of it. The primary care provider has the ability to fill in these gaps, to identify other local community based resources that could meet those needs and to be sure that they are addressed to the patient's and/or family's satisfaction.

6. Sexuality

6.1. General

A growing number of individuals with spina bifida are reaching sexual maturity. However, the topics of sexuality, sexual activity and reproduction are often overlooked or intentionally omitted in the primary care of individuals with disabilities. Parents are more likely to ask primary care providers how to stop these activities than how to appropriately address this normal developmental process. Both parents and health care professionals can be rather pessimistic regarding the potential of persons with a disability to enjoy intimacy and sexuality in their relationships. Most adolescents with spina bifida desire to marry and have children [2]. Fertility is generally preserved in females with spina bifida; it is reduced in males. Less than 20% of individuals with spina bifida have sought information regarding their sexual or reproductive function. Only 16% of those who were sexually active used contraception [24]. When sexual education occurs, it is more likely to take place at school than at home or the physician's office [8]. It is unlikely that the education provided took into consideration the unique challenges for individuals with spina bifida including the ability to achieve orgasm and genital sensitivity. Surveys of individuals with spina bifida demonstrate that this is an area where additional education is desired and a topic that would be discussed if raised by the physician. Such information and topics should be introduced at an early age to facilitate later discussions.

However, neither parents or physicians can ignore the physical changes that occur during puberty nor the significant mismatch this often represents compared to the affected individuals developmental status. The National Center on Child Abuse and Neglect reports that children with disabilities are sexually abused at a rate 2.2 times higher than that of children without disabilities [24]. Individuals with neurodevelopmental disabilities are much more likely to experience idiopathic precocious pubertal changes with an incidence approaching 20% among females with spina bifida compared to 0.6% in the general population. The average age of menarche in girls with spina bifida is 10.9–11.4 years compared to 12.7 years in the general population [15, 24].

Independence in basic self-care tasks is a central component of successful sexual and social maturity. Limitations in ambulation and self-care activities have been reported to be important determinants of health related quality of life in children and adolescents with spina bifida [20]. The strongest relationship between life satisfaction ratings and having spina bifida may be self care ability [2]. There is no clear linear inverse relationship between condition severity and health related quality of life in children with spina bifida [20]. Children with disabilities learn self-care tasks and seek independence later than their typically developing peers. Physical limitations and this lack of independence interfere with normal psychosexual development, resulting in limited dating relationships in this population. A study by Lassman found no difference in gender distribution among sexually active patients, suggesting that sexual maturation and discovery is equally complex for the male and female adolescent with a physical impairment [19]. They may need a variety of supports well into adolescence and adulthood to achieve and maintain these important developmental milestones: frequent cues, supervision, formalized instruction, adaptive technology, and reinforcement [11]. Self identi-

fied obstacles to establishing relationships among individuals with spina bifida include self-confidence, continence and wheelchair use; continent patients were twice as likely as incontinent patients to have a partner. Patients without hydrocephalus were 3.2 times more likely to have a partner than those with hydrocephalus and approached the general population rate [31].

6.2. Men

Initiation of and access to sexual activity in males with spina bifida is delayed compared to normal healthy peers. 40% of men with spina bifida engage in sexual activity but 80–100% of post pubertal men with spina bifida report normal sexual desires and fantasies and are actively interested in sexual activity.

Infertility is also a common problem with reported paternity rates ranging between 56–73%. The overall prevalence of erectile dysfunction in adult men with spina bifida is approximately 75%. This is significantly affected by the presence of sacral reflexes and neurologic lesion level though no absolute anatomic level can be established. In one study, 64% of men with lesion at T10 or lower obtained erections compared to only 14% with a lesion above T10 [4]. Cass also reported that the majority of male patients with lesions below L3 had more penile sensation, erections, and ejaculations than those with lesions above L2 [9].

6.3. Women

There is limited information on specific gynecological conditions in women with spina bifida. Instead data is often extrapolated from women with similar disabilities such as spinal cord injury and multiple sclerosis. However, recognized measures of appropriate health care access for all women show clear evidence of disparities; 45% of women with disabilities have had mammography in the past 2 years compared to 63% in the nondisabled population [17].

Women with spina bifida are at increased risk (20–50 fold increase) of having a similarly affected offspring compared to the general population (1:1000 live births). We have know since 1991 that supplementation of a woman's diet with folic acid prior to conception decreases the risk of spina bifida and other neural tube defects by as much as 70%. There are pregnancy complications unique to women with spina bifida. No standards for routine obstetrical care currently exist. In addition, there are specific medical and surgical challenges associated with some of their frequent secondary conditions: kyphoscoliosis, ventricular shunts, and previous neurogenic bowel and bladder procedures [15].

Compared to control subjects, women with disabilities are less likely to use hormonal contraception (11.7 vs. 19.7%), are more likely to have had a hysterectomy (8.9 vs. 4.3%), and are significantly more likely to us no method of birth control at all (41.9 vs. 33.4%) [15]. Women with spina bifida often have osteoporosis; oral contraceptives composed mostly or completely of progesterone (injectable medroxyprogesterone acetate) may potentially exacerbate this problem. Oral contraceptives composed mostly of estrogens (pills, transdermal patches, vaginal contraceptive rings) have the tendency to promote a hypercoaguable state in women and the immobility of some women with spina bifida may make this more pronounced and increase their theoretical risk for deep vein thrombosis. Some antiepileptic medications induce hepatic enzyme activity and decrease the effectiveness of oral and implanted contraceptives [24]. The use of intrauterine devices should be avoided in women with a history of chronic urinary tract infections or impaired pelvic sensation, frequent findings in this population. Problems with physical dexterity may make the use of barrier devices difficult.

7. Latex sensitivity

Children with spina bifida are the patient population at greatest risk for latex sensitization. Some reports suggest that up to 73% of them will exhibit allergic signs and symptoms. It appears that the number and also the type of operations is the most important factor implicated in this IgE mediated reaction. Patients with higher numbers of urologic and orthopedic procedures seemed to be at greatest risk for sensitization and eventual allergic symptom development. There have also been studies to suggest that the number of operations in the first year of life is an important variable. Efforts to define the sensitizing effect of multiple ventriculoperitoneal shunt procedures have produced inconclusive results. The treatment of choice is prevention by limiting/eliminating latex exposure [21].

8. Obesity

Lifestyle-related diseases, such as cardiovascular disease and diabetes mellitus, will have an increasing

impact on persons with spina bifida as their life span increases well into adulthood. Therefore, more attention towards a healthy lifestyle by this group and their health care providers is warranted [7]. Physical inactivity, obesity and poor aerobic fitness are known to be independent risk factors for these conditions in both ambulatory and non-ambulatory persons with spina bifida. Though the literature is somewhat limited, recent studies have demonstrated this triad of risk factors to be present in adolescents and young adults with spina bifida; interventions should be designed to address all three issues. No causal relations can be established whether adolescents and young adults with spina bifida are inactive because they are unfit or whether they are unfit because they are physically inactive.

In some cases reducing caloric intake may be more important in preventing obesity than increasing daily physical activity or fitness [6].

Studies by Buffart reported 35% of adolescents and young adults with spina bifida are obese while others have suggested a figure as high as 58% [6]. The International Classification of Function, Disability and Health (ICF) (www.who.int/icidh) would categorize obesity as a secondary manifestation in the domain of Body Function/Structure. A large body of literature documents the effect of obesity on person-environment interactions that will affect a person's developmental stage, their physical status, their nutrition and their level of activity [28]. Because of inconsistent study results, ambulatory status alone is not a reliable predictor of obesity.

Controversy still exists on the best way to assess and monitor obesity in this population. It has been suggested that Body Mass Index (BMI) may overestimate body fat in persons with spina bifida because height is underestimated due to neurologic deficits in the lower extremities and trunk. Modifications to this calculation have included the substitution of arm-span measurements or specific body segment lengths for height. Measures of skin-fold thickness have also been used successfully to assess fat stores [6].

8.1. Summary

The comprehensive care of individuals with spina bifida, young or old, requires timely access to a knowledgeable primary care provider as well as appropriate subspecialists. Care organized along the principles of a Primary-Care Medical Home and built on a framework of care coordination and partnership between care providers, patients and families is essential. This framework cannot be limited by age. As the lifespan of individuals with spina bifida increases, both primary and specialty care providers must address issues of quality of life and health, not just the quality of health care. Public advocacy, better training of a wider variety of providers and the necessity of transition planning and implementation must improve as well. Spina bifida is no longer simply a "pediatric" disease and models of health care cannot simply be an extension or repetition of what has always been done.

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