SPINA BIFIDA

*Split Spine*

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Introduction

Every year, almost 120,000 babies are born with a birth defect. That means that 1 in every 33 babies born per year will have a birth defect (http://www.cdc.gov/ncbddd/birthdefects/facts.html).

One of the most common birth defects in the United States is Spina Bifida (SB). Currently about 3,000 babies are born each year with this defect (http://www.cdc.gov/ncbddd/spinabifida/data.html). To provide further information concerning Spina Bifida, this paper will provide the following:

- Background
- Diagnosis of SB
- Symptoms and Progression
- Specific needs for those with SB
- Specific Tests
- Prognosis
- Therapeutic Recreation Implications
- Resources

Background on SB

Neural Tube Defect

Spina Bifida is a defect that occurs along the neural tube within two to three weeks of development while within the womb. The neural tube develops along the back of the embryo eventually forming the brain at the top part of the tube with the remainder becoming the spinal cord. Spina Bifida occurs when the neural tube does not develop completely, exposing the spinal nerve (http://www.ninds.nih.gov/disorders/spina_bifida/detail_spina_bifida.htm). The
following video shows the development of spina bifida:

https://www.youtube.com/watch?v=jlDZA2PNW2o

**Causes**

It is actually unknown what the exact cause of Spina Bifida is. It appears to be a random genetic defect. Though doctors are unsure what the specific cause of Spina Bifida is, they have identified many possible risk factors to the development of Spina Bifida. A deficiency of folic acid is the most common risk factor. Folic acid is found in foods such as leafy, green vegetables, nuts, beans, and citrus fruits. Women who are trying to become pregnant are encouraged to increase their intake of folic acid in hopes that this could prevent the development of Spina Bifida. Additional risk factors have been linked to environmental factors such as obesity, diabetes in the mother, and some medications. Additionally, genetic factors such as history of neural tube defects can also indicate a higher chance of Spina Bifida (http://www.mayoclinic.org/diseases-conditions/spina-bifida/basics/risk-factors/con-20035356).

**Diagnosis of Three Forms of Spina Bifida**

As shown in the picture below, there are three forms of Spina Bifida that vary in degree of severity.
The mildest form of Spina Bifida is known as Spina Bifida Occulta. Spina Bifida Occulta occurs when there is a small opening or gap between two vertebrae, however, there is no protrusion of the meninges or the spinal cord.

Meningocele is the least common form of Spina Bifida. Through the small gaps between vertebrae, the meninges seeps out of the spinal canal forming a sac that protrudes from the baby’s back. This is not a very dangerous form and can be easily removed without harm through surgery.

The most common and most damaging form of Spina Bifida is Myelomeningocele. This occurs when there are many openings in the vertebrae. The meninges and the spinal cord are pushed out of the opening and are visibly protruding from the child’s back. Occasionally there will be a thin covering of skin covering the sac, but many times the spinal cord, tissues, and nerves are exposed to the open. Because of the exposure, the child can gain very serious and even life-threatening infections. (https://www.schn.health.nsw.gov.au/parents-and-carers/fact-sheets/spina-bifida)

Symptoms and Progression

There are many different symptoms that result from Spina Bifida. Some of the symptoms include the following:

- Orthopedic Problems — such as deformed feet, uneven hips and a curved spine (scoliosis)
- Muscle weakness of the legs, sometimes involving paralysis. If the lesion is towards the top of the spine, paralysis is more common. If there is any movement or sensation in the legs, most people will be able to walk with the help of braces (see table below).(http://spinabifida.org.nz/loss-muscle-strength/)
- Bowel and bladder problems. Almost all people with Myelomeningocele have to wear a catheter for their entire lives to regulate their bladder problems.
- Hydrocephalus comes from the CSF (cerebrospinal fluid). The Cerebrospinal fluid goes into the ventricles of the brain, causing them to be enlarged. This pushes up against the brain and the skull, enlarging the head in response. Shunts are put in place to drain the water from the brain into the digestive system.

- Seizures, especially if the child requires a shunt.

Unless there are other brain abnormalities, many people with spina bifida and even hydrocephalus, may have average or above average intelligence. Hydrocephalus infections may bring about Meningitis which could cause learning disabilities or difficulties in focusing.

In addition to challenges with mobility and learning, many children with spina bifida have difficulties with bowel and bladder function, latex and certain food allergies, skin problems such as pressure ulcers, orthopedic concerns and digestive conditions. Obesity and early development of puberty can be seen in association with spina bifida. Depression, anxiety and concerns about sexual function may occur as children with spina bifida get older.
Specific Needs

Because the type and level of severity differs among people with Spina Bifida, each person with condition faces different challenges and may require different treatments.

Operation needs differ between type and severity of Spina Bifida. A child with Meningomyelocele usually is operated on within two to three days of birth. This prevents infections and helps save the spinal cord from more damage.

A child with Meningocele is usually treated with surgery, and more often than not, the child is not paralyzed. Most children with this condition grow up fine but should be checked in case other serious problems arise. A child with OSD is usually recommended to see a surgeon. Most experts think that surgery is needed early to keep nerves and the brain from becoming more damaged as the child grows. Lastly, Spina Bifida Occulta usually does not need to be treated.

As with differing surgery needs there are also other differing treatment needs and tools. People with Spina Bifida may have the following needs:

- A Back Brace to support and realign the spine
- Extra time moving to and from locations
- Special seats and space for wheelchair accessibility
- Vision aids
- Hearing Aids
- Splints, casts, leg braces, canes, crutches, walkers, or wheelchairs for mobility
- Assistive technology such as pressure re-distributing seat cushions and bath chairs (http://kidshealth.org/en/parents/spina-bifida-factsheet.html)
Professionals agree that the best way to manage Spina Bifida, as with most other disabilities, is with a team approach. Members of the team may include neurosurgeons, urologists, orthopedists, physical and occupational therapists, recreational therapists, psychologists and medical social workers.

With proper treatment people with spina bifida may lead full lives. According to the Spina Bifida Association of America, 90% of persons with spina bifida live to adulthood, 80% have normal intelligence, 75% play sports and other activities.

Specific Tests

Pre-Birth Diagnosis

Before birth, babies may be tested for spina bifida. There are three different test procedures. These tests include:

1. A blood test during the 16th-18th weeks of pregnancy. This is called the alpha-fetoprotein (AFP) screening test.
2. An ultrasound of the fetus.
3. Amniocentesis- a test where a small amount of fluid from the womb is taken through a thin needle.

Post-Birth Diagnosis

After birth, spina bifida may be visible on the baby's back in the form of a hair patch of skin or a dimple. Confirmation of spina bifida then comes through an X-ray, MRI, or CT scan.

Interestingly, Spina Bifida Occulta may not be diagnosed until much later in life, if diagnosed at all. Many cases go undiagnosed because the severity is so miniscule.

Tests and Treatment Procedures

There are many other procedures and tests persons with spina bifida may have to encounter. 70-90% of children with myelomeningocele develop hydrocephalus, a buildup of fluid around the brain. When fluid can’t circulate normally it collects around the brain, causing the head to be enlarged. Brain damage and mental retardation can occur without treatment. To treat, doctors usually surgically insert a tube that drains the excess fluid.
Most children with myelomeningocele have a change in their brain position. This can block fluids and contribute to hydrocephalus yet in most cases there are no other symptoms associated with the blocked fluids. Rarely, serious problems do occur, such as breathing or swallowing difficulties, where doctors may perform surgery to relieve pressure on the brain.

Patients may develop a tethered spinal cord, where surgery may be vital. Symptoms may include leg weakness, scoliosis, pain in back or legs, changes in bladder function, and worsening leg function.

There are many tests and procedures for patients with spina bifida who have kidney and bladder problems. Blood tests, ultrasounds, and renal scans may provide needed information on how to treat specific issues. A clean intermittent catheterization may be important to empty the bladder, medications are often used to prevent and treat infections, and sometimes surgery is needed to ensure a proper bladder. (http://www.chadkids.org/urology/urology_parents_urological_spinabifida.html)

**Transitional Testing**
An important aspect of testing includes transitional testing, a way to measure the ability for a patient to transition from childhood through adolescence to adulthood. One popular transitional test is the Quality of Life Assessment: Adolescent Self-Management Independence Survey which focuses on two key factors: Independent Living and Condition. A surveyor will assess the person’s ability to complete daily functions like taking medicine, refilling prescriptions, personal care, keeping appointments, etc.

**Screenings**
Screenings for assistive devices (visual aids, wheelchairs, etc.) is vital to maintain quality of life for people with spina bifida. These screenings may test the following:
- Hand function
- Social skills
- Activity level
- Cognitive level (remember, the more the spinal cord is damaged the greater the chance for learning disabilities).

**Prognosis**

People diagnosed with Spina Bifida have wonderful opportunities that lie ahead of them. The likely course that they will take, although filled with life-long medical attention, will allow them to still have a high quality of life and allow them to participate in the same activities as the general population.

Statistics show that approximately 90 percent of children diagnosed with Spina Bifida will live well into adulthood, about 80 percent have average intelligence, and 75 percent are a part of competitive sports and organized recreation. Studies have followed children born with Spina Bifida throughout their lives and have discovered that these groups of individuals attend college at the same rate as the general population, and most have a current and active job.

“They may have some special challenges but their condition does not define who they are. They still have dreams and determinations to reach their goals; they hold diverse and meaningful jobs; they get married and have families; and they go on to make significant contributions to their communities.

There are people with Spina Bifida who are world-class athletes, politicians, actors, writers, musicians and doctors. They help to educate society about what is possible, and to be a part of that journey is extremely rewarding” (http://spinabifida.org.nz/might-future-hold-baby/).

Thanks to the active medical knowledge we are blessed with, continued advancements and discoveries will lead to the improvement of care for people with Spina Bifida over the years to come.
Therapeutic Recreation Implications

Those with Spina Bifida, deserve to have a high quality of life. Through Therapeutic Recreation, people can improve and maintain muscular function. Activities such as swimming, horseback riding, wheelchair tennis, adaptive dance and skiing, etc… all lead to these improvements in muscular function.

Leisure Education allows people with Spina Bifida to see their potential and to learn what abilities they have that they can use in different activities. They also gain new skills from these activities and learn how to use adaptive equipment. Being involved in sports provides context for social interaction and feedback from others.

Here are some helpful websites for those who are looking for places and ideas that use therapeutic recreation to treat Spina Bifida:

http://spinabifidaassociation.org/resource-directory/recreation/

Resources

For more information regarding Spina Bifida, please review any of the following sources:

- Spina Bifida Association
● Mayo Clinic
● Center for Disease Control and Prevention
● Utahspinabifida.org
● University of Utah Health Care