Managing Skin Health in Obese Children with Spina Bifida: An Overview and Case Study

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Chronic wound and skin care issues in obese children tend to occur in specific disease-related groups such as patients with neural tube deficits. While the incidence of neural tube deficits has declined as a result of increased awareness about the importance of prenatal folic acid intake, neural tube deficits remain some of the most common congenital anomalies. General care of spina bifida patients must address their physical limitations, structure, decreased sensation, limb weakness, and psychosocial needs related to dependence on others and being "different." Patients and their families also face the challenge of preventing and treating skin breakdown. As illustrated in the case study of one 14-year old patient, wounds occur and recur for a wide variety of physical, social, and environmental reasons. When skin breakdown occurs, a multidisciplinary team approach that incorporates physicians, physical and occupational therapists, nutritionists, social workers, and wound care specialists has been found to be most effective in restoring skin integrity. Patient and family, as well as healthcare providers with whom they interact, need to be educated on the complexities of care provision. Additional research into specific conditions related to this population to help healthcare professionals provide evidence-based care is needed. KEYWORDS: spina bifida, skin health, pediatric, obesity management

Key Points.

In the author's experience, obese pediatric patients with chronic skin care issues tend to be concentrated in specific disease-related populations. Unlike their adult counterparts, overweight children rarely have chronic skin care issues because they have not developed the comorbid conditions that predispose to skin failure. However, in the author's experience, wounds tend to be chronic in obese patients with neural tube deficits (NTD). Life issues affect the patient/family unit in a myriad of ways, creating challenges in the provision of care. While the incidence of NTD has declined in recent years and as many as 50% to 70% of NTD cases in the US could be prevented with adequate ingestion of folic acid,[1] healthcare professionals will continue to see children with NTD.

The purpose of this overview is to summarize the etiology of spina bifida and to discuss skin health management issues encountered by patients, families, and medical professionals. A case study is included to illustrate these challenges.

What is Spina Bifida?

Neural tube deficits result from abnormal development of the spinal cord and associated neural tube structures; diagnoses include myelomeningocele (spina bifida), meningocele, and lipomeningocele.[2] Spina bifida is one of the most common congenital anomalies in the US with an incidence rate of approximately 1:1,000 live births.[3] The level of the patient's lesion determines his/her amount of motor and sensory function. For example, lesions at S-1 and S-2 generally have neurogenic bowel and bladder as well as decreased innervation to the distal lower extremities. Lesions in the lumbar vertebrae result in paralysis and decreased sensation more proximally.[2] The higher the lesion, the more likely the patient is to be wheelchair-bound.[2,4] Some patients with spina bifida can ambulate with aids such as splints, braces, and/or walkers. However, as they grow, limb weakness can increase. This can be attributed to high energy requirements for walking, increased body weight, and deterioration of the lower extremity muscles needed for walking — ultimately, these patients become wheelchair-bound.[2,5] Decreased mobility and easy muscle fatigue to lower extremities engenders a more sedentary lifestyle, which contributes to their obesity problems.

Case Study: *Ms. G is a 14-year-old African American. She is in seventh grade. Born with a lumbar meningomyelocele, cloacal exstrophy, and imperforate anus, Ms. G. is insensate below the waist and has small, flaccid legs. Her urinary incontinence is managed with diapering and she has had a colostomy since birth. Ms. G lives in an apartment with her two able-bodied younger brothers and her mother, a student at a local community college who also works. Ms. G has a very independent nature and prefers to care for herself.*

Weight and Spina Bifida

Excessive weight is a common problem in people with spina bifida. After the age of 6 years, 50% of children with spina bifida are overweight; 50% of teens and adults are obese.[6] Studies have shown decreased lean body mass and basal metabolic rate in people with spina bifida as compared to their peers.[6] Fiore et al[7] note that in myelomeningocele patients, both neurologic and systemic dysfunctions contribute to obesity and malnutrition. Their study showed that overweight patients with spina bifida had an energy intake lower than their recommended daily allowances. No correlation was found with degree of motor impairment, leading the authors to speculate that obesity in these patients is the result of complex interactive factors, not simply related to decreased mobility and excessive caloric intake. Endocrine problems such as precocious puberty and growth hormone deficiencies often have been noted in the NTD population.[2] In a study by Shepherd et al,[8] patients with spina bifida over the age of 3 to 4 years were found to have notable depletion of body cell mass and total body water with maldistribution of water and increased percentage of body fat above that expected. These findings were more pronounced in female patients and persons with high lesion levels (ie, thoracic). It was noted that these changes could cause metabolic and nutritional maladaption in times of stress. In addition, professional experience has shown that because people with myelomeningocele also tend to be of short-stature due to scoliosis (curvature of the spine), as well as to have lower extremity abnormalities, a greater percentage of the body's weight is carried in a smaller area, exerting higher pressures on posterior and distal supportive structures, which results in skin breakdown.

Ms. G has a shortened trunk and moderate scoliosis. The majority of her body weight is located at her waist, stomach, and hips. Because of her mother's busy schedule, Ms. G began cooking for the family and discovered her true passion — it is difficult to get her out of the kitchen. In order to cook in an apartment kitchen, Ms. G sits on the arm of her wheelchair pulled as close as she can to the kitchen counter or stove. Although she is aware of nutritional guidelines in general, she makes what she and her brothers like, what they will eat, and what they can afford.

Physical Abnormalities

Children with spina bifida can have a variety of orthopedic problems, from clubfeet to congenital hip dysplasia to spinal deformities.[6] Ankle/foot orthoses are used to improve gait and decrease energy consumption by keeping the foot and ankle in proper alignment for movement.[9] Lower limb anomalies as well as higher lesions may consign the person to life in a wheelchair. Scoliosis and kyphosis (exaggeration or angulation from the normal thoracic vertebrae column) are common in this population and result in serious medical issues such as restrictive lung disease and difficulty sitting.[10]

Orthopedic deformities lead to skin problems. Experience has shown that when the spine is surgically repaired, patients who previously had no skin breakdown can begin to present with pressure ulcers. Change in weight distribution from improved posture results in new pressure points that their old wheelchair cushions do not accommodate. Patients must have their wheelchairs and cushions reevaluated and adjusted after spinal instrumentation.

Patients with kyphosis face other problems. Thin layers of skin cover the bony protuberance of the gibbus on their back and unless a customized wheelchair is used higher than normal pressure is exerted on this area, leading to difficult-to-heal wounds. Due to the close proximity of the spine and often a ventriculoperitoneal shunt placed to drain cerebrospinal fluid, infection is an early life-threatening complication. For patients who must use long-distance public transportation, this deformity can be a major difficulty. Also, proper sleep positioning on his/her side is important from a respiratory and skin management standpoint for the child with a significant gibbus; the use of a pressure redistribution surface is encouraged. Splints and braces often are used for support, stability with ambulation, and positioning of the extremities. Patients with altered sensation to distal limbs may not be aware of abnormal movement or tightness of the orthotic until a wound has formed — a variety of problems with orthotic devices from extensive athlete's foot due to sweating to simple blisters and pressure ulcers to extensive callusing at the site of repetitive friction have been noted at the author's facility. These calluses can become quite large and subsequently cause pressure ulcers. Follow-up appointments with medical specialists such as physical therapists, occupational therapists, orthotists, wound care specialists, and physicians are important for proper positioning, ambulation, and support surface management.[11,12]

Luckily, Ms. G does not have a large kyphosis in relation to her scoliosis. Although her scoliosis to date has not caused any respiratory problems, it affects her seating pattern: she has a tendency to lean to the right side. Her wheelchair cushion has been adjusted to accommodate

increased lateral pressure. When Ms. G does not use her chair cushion, she exerts higher pressure on her right ischium and posterior thigh.

Ms. G will not consent to surgical repair of her scoliosis. Even though her overall seating pattern has not changed, growth and weight gain have necessitated upgrades to and re-evaluation of her cushion and wheelchair. She frequently misses appointments at the wheelchair clinic due to transportation issues.

Impaired Sensation

Impaired sensation below the level of the spinal defect is a major contributor to skin breakdown.[6,11-13] Patients (and parents until the child is old enough) are taught to inspect skin in the morning, evening, and whenever they get out of their wheelchairs. Skin under splints and braces also should be examined on a regular basis. If redness occurs, extensive padding is discouraged because it will increase pressure on the site and change the fit of the brace/splint, creating more pressure-related breakdown. Thin adhesive dressings placed over the reddened area can work well under prosthetics. Leaving the brace or shoe off for short, regular intervals during the day is encouraged. Orthotists should be consulted to assess the brace once a problem has been identified or significant growth has occurred. Patients are encouraged to wear cotton tube socks under ankle/foot orthotics to help manage diaphoresis and to guard against friction. Wheelchair-bound as well as insensate patients should learn proper transfer techniques. Scooting along a hard surface instead of using one's wheelchair should not be encouraged.

Occupational and physical therapists and nurses can teach parents and patients proper techniques for fitting clothing over prosthetics, prosthesis care, and principles of skin inspection. First, patients/parents should inspect for foreign objects that may be located in the shoes or splints and be aware of brace or splint failure (cracks or frank breakage of the prosthesis), skin irritation or breakdown on their foot or ankle related to prosthetic device wear, and wet clothes or devices used for incontinence that can lead to chafing, fungal overgrowth, and skin breakdown. Excessive material in seating areas can cause pressure ulcers; thus, parents and patients are encouraged to inspect not only the skin in relation to a brace, but also the buttocks, groin, and sacral areas daily for signs of pressure, friction, or moisture-related changes. Also, patients with insensate limbs must take precautions to prevent their feet from getting caught in the wheels of their chair and from running into stationary objects with their feet and legs.

Because Ms. G is completely insensate below the waist and has never been able to walk, braces and splints have not been an issue. Low-income apartment housing is neither spacious nor easy to navigate in a wheelchair. Ms. G has taken the leg rests off her wheelchair in order to allow easier access to the kitchen, bedrooms, and bathroom, as well as to let her flaccid, insensate legs dangle freely.

During one hospital admission, new wounds were noted on Ms. G's left fourth and fifth toes. When asked how this occurred, she responded that she ran into the doorjamb with her chair and her foot got caught between the chair and the wall. On another admission, she was noted to have two new posterior heel pressure ulcers. Because she does not use her leg rests, wound origin was uncertain — Ms. G is rarely in bed or lying down when she is not in the hospital (a common cause of heel ulcers). It was finally determined that she had purchased and worn new shoes without trying them on in the store and they were a size too small. The result was two new pressure ulcers within 48 hours.

In the summer, Ms. G tries to participate in as many activities as her brothers as possible. At the public pool, she gets herself out of her wheelchair and scoots over the hot concrete to the edge of the pool where she can get into the pool using the non-ladder steps. At one point, these actions caused a combination of wounds to her knees — the rough, hot concrete inflicted abrasions and elements of a burn and the public pool contaminated the wounds. During the course of treating the non-healing wounds, Ms. G's mother revealed that her daughter constantly drags herself across the floor to get items she needs because it is easier and faster than trying to maneuver her wheelchair in their apartment. Small "rug burns" on Ms. G's lower extremities and feet are a common occurrence.

Psychosocial Challenges

Obstacles to learning. Patients with NTD and their families experience numerous psychosocial challenges. Many myelomeningocele patients have an Arnold Chiari Type II malformation,[14] a defect in the central nervous system that causes displacement of the brainstem or cerebellum into the cervical spinal canal, obstructing flow of the cerebral spinal fluid. Because this can lead to hydrocephalus, a ventriculoperitoneal shunt frequently is placed. Cognitive skills may be retarded due to neurologic considerations, academically separating these patients from their peers.

As a group, children with spina bifida and hydrocephalus often have learning disabilities and can be socially as well as developmentally delayed[15]; children with average IQs have better verbal than math skills and tend to have poor perceptual motor skills that affect eye-hand coordination. Persons with higher lesions have a greater possibility for lower intelligence and motor skills and children with more severe hydrocephalus also have a lower IQ.[6] Upon entering school, the child with spina bifida and hydrocephalus should have psychological or neuropsychological testing that considers individual strengths and weaknesses to ensure appropriate classroom placement.

Ms. G is 14 years old and in seventh grade (usually children in this grade are 12 years old); she is behind in school due to her many hospitalizations for various illnesses. Ms. G does not like school. She has difficulty concentrating on her work. She has attended school during her long-term admissions to the hospital but she frequently did not complete her schoolwork because her mother was not available to help her.

Ms. G does not like to read — even after reading one chapter, her comprehension and/or recall is poor at best. She dismisses this with the excuse that she is "going to be a chef anyway."

Social issues. Living with myelomeningocele can create a wide variety of social problems.[16] Holmbeck and Faier-Routman[4] investigated psychosocial adjustment and family relationships in patients with spina bifida. For mothers of patients with higher lesion levels, "more attachment to their children, less family conflict, and greater willingness to grant autonomy to their offspring" was noted; the converse was found in patients with sacral level lesions. The authors, who had hypothesized the opposite, believed the results of their study could best be explained by the "marginality" hypothesis.[4] In families where the child required greater amounts of care early on, the parents were more likely to allow children to do whatever they could for themselves. The family as a unit tends to be involved in this child's care. Those with lower level lesions require less total care and more focused care from the primary caregiver, usually the mother. This situation creates a higher protectiveness on the part of the mother, dependence in the child with spina bifida, and increased conflict within the family unit.

Outside the family unit, children such as Ms. G are "tweeners" — ie, they fall between more clearly defined groups and cannot fully identify or be identified with either. Children with lower lesions may not appear to be frankly handicapped (as is the child in a wheelchair) but although they may be able to walk, they cannot keep up with able-bodied peers or participate fully in "normal" physical activities due to motor sensory deficits.

Also, children with spina bifida can have motivational problems while in school if they have become too dependent on their parents.[6] Social immaturity and passiveness have been noted in children with spina bifida. Holmbeck et al[17] found these children tend to have fewer social contacts outside of school and are frequently dependent on adult guidance for decision making on all levels. Children with lower socioeconomic status and physical disabilities have additional risks for psychological adjustment difficulties. It is important to children to look and/or be like their friends. Appearing too dissimilar can create a further chasm with their schoolmates. Physical malformations as well as academic challenges evident in persons with spina bifida can be very noticeable.

Through the author's efforts, Ms. G had an opportunity to attend the United Ostomy Association Youth Rally Camp for children with continence issues and ostomies. She was interested but her mother would not allow her to go unless she could go along to the camp and stay with her. Her mother said that they had never been apart and she couldn't let her go away without accompanying her.

When talking with Ms. G about her life, few friends are mentioned. Most of her contact with schoolmates is through school or phone. She talks about things she has done with her mother, brothers, aunts, and/or cousins but rarely discusses social events with non-family contacts. When larger groups of people such as therapists, volunteers who come to play with or deliver things to the children, or medical teams who travel in packs come to Ms. G's hospital room, she gets very quiet. She says can't do what the other kids do so they don't want to "hang with me." While she is hospitalized, Ms. G has an active social life: she and other "frequent flyers" get to know each other and the hospital staff quite well. It is not socially acceptable in a hospital to avoid sick people!

Financing Special Needs

The need for access to complex medical care creates financial difficulties. Clients with a NTD will have multiple medical practitioners — eg, a pediatrician with expertise in spina bifida, orthopedist, urologist, neurologist, neurosurgeon, orthotists, and physical, occupational, and/or speech therapists — who must be seen on a routine basis. Medications are needed and medical supplies such as wheelchairs and cushions, braces, and splints must be upgraded as the child grows (often custom made). Devices such as catheters, diapers, ostomy equipment, and (sometimes) special beds will be necessary for daily care. Special vehicles to transport wheelchair-bound patients (if the family can afford them) or access to public handicap transportation must be made available. Such needs strain the family's budget. Many patients with spina bifida who are followed by the author's institution have Medicaid insurance, indicating their family income is very low. Delays in upgrading or replacing high-end medical supplies such as wheelchairs, cushions, and specialty beds due to Medicaid rules and paperwork are common; so is family inability to afford

payment for such items. Often what may be perceived as "non-compliance" is in reality the inability of the patient/family to afford treatments, medical supplies, or transportation to appointments. It is critical to involve a social worker in these situations to help the client navigate the insurance and medical system more efficiently.

Ms. G frequently misses follow-up appointments for routine health, as well as wheelchair clinic screening, appointments. Ms. G and her mother often have trouble arranging and securing money for local handicap-accessible transportation to bring them to their appointments. Traditional Medicaid dictates the timing on wheelchair upgrades and repairs so Ms. G and her mother try to take care of any problems. When Ms. G's cushion became uncomfortable, an old couch cushion was added to the seat. Torn vinyl or missing caps/covers are repaired with duct tape. When Ms. G's ischial wound opened and drained, mother and daughter rinsed the wound and left it to drain into her diaper to avoid the extra cost of dressings.

Wound Care Provision

Wound care principles for the child with chronic wounds are the same as in adult patients. Accurate and regular assessments of the wounds and relevant systemic parameters related to healing are the critical underpinnings of any wound care plan.[18] The goal is to match wound care needs to treatment options. Assessing the primary caregiver's ability to manage the needed wound care at home, as well as his/her understanding of the regimen, is vital. Treatment decisions must take into consideration what is financially reasonable for the patient/family unit in order to maximize ability to meet wound care needs. Rolstad et al[19] summarize: "Wounds do not occur in isolation from the total patient. Consequently, the principles of effective wound management must incorporate a holistic approach to the patient. Failure to address any one of these principles jeopardizes care and may result in an unhealed wound, complications, or recurrence."

If a wheelchair-bound patient develops pressure ulcers in a weight-bearing area, the author's facility prepares the wound bed for reconstructive surgery. The patient with a long-standing wound must undergo evaluation for osteomyelitis, which includes laboratory and diagnostic imaging exams.

A team approach has been found to be the most effective way to manage these cases. After assessing all of the patient's and family's needs, a team is assembled. Constant communication and coordinated visits keep management goals clear. Establishing routine follow-up visits with team members is vital. Physicians monitor medical and growth needs; orthotists and physical and occupational therapists minimize problems arising from outgrown chairs and splints or braces and worn wheelchair cushions as the patient grows.

Involving a WOC nurse when wounds develop or for skin maintenance education has worked well in the author's facility. Although not normally expected in the pediatric population, wounds due to venous congestion and/or hypertension can occur in wheelchair-bound persons. Their insensate limbs and dependent position create a roughly 90-degree bend in the ileofemoral vessels; the author suspects the weight of the trunk creates a constant pressure gradient that may impair or occlude venous return leading to tissue failure. Spina bifida patients' lower extremity wounds mimic venous ulcers seen in the adult obese population. Without compression, wound healing is only temporary. Research in this pediatric population is needed.

When her mother failed to notice a pinching or bunching of Ms. G's diaper in her right groin fold, a deep wound resulted. Within 3 days of swimming in the public pool with this open wound, Ms. G developed a fever and a greenish, thick drainage from the wound. She was admitted to the author's facility for intravenous antibiotics and local wound care. The wound was treated with a papain urea-based product to liquefy the necrotic tissue in the wound bed, covered with normal saline-dampened gauze, and secured with a dry cover dressing and cloth tape. Her bilateral knee abrasions were treated with a hydrocolloid dressing. Because Ms. G is inclined to move around a great deal without regard for her lower extremity dressings, a self-adhesive stretch wrap was loosely applied over her dressings. The wounds progressed and after a short stay, Ms. G was discharged home, only to be readmitted to the hospital within a month of her discharge date for the same problem: a groin wound infection. Radiologic images were taken and showed osteomyelitis had developed in her pelvis. Ms. G had to be hospitalized for 8 weeks to receive the necessary antibiotics. Local wound care included whirlpool therapy, papain-urea compound, gauze dressings, and transparent adhesive film (TAF). Once the necrosis cleared, hydrotherapy was discontinued and her wound dressing was changed to amorphous hydrogel with silver covered with gauze and secured with TAF.

Within 6 months, Ms. G and her mother returned to the author's facility with a new wound to her right hip. They were unable to identify a causative agent. Laboratory values indicated a low serum albumin level, a high C-reactive protein level indicative of an inflammatory process, and wound cultures were positive for methicillin-resistant Staphylococcus aureus. X-rays showed bony changes consistent with the osteomyelitis for which she had been previously treated. Intravenous antibiotics along with negative pressure wound therapy (NPWT) were initiated. Ms. G was placed on a low-air-loss bed and nutritional supplements. A plastic surgeon was consulted for wound closure. After 6 weeks of antibiotic therapy, Ms. G had a myocutaneous flap and osteotomy. In the second postoperative week, the wound partially dehisced, requiring NPWT to be restarted. The wound responded well and after 10 days, Ms. G was discharged home with an appointment for wheelchair and chair cushion evaluation at the author's clinic. The appointment was not kept.

Within another 6 months, Ms. G was readmitted with another major wound, this one to her right ischial area. She also presented with new wounds to her heels and knees bilaterally and to her right lateral malleolus. She was given antibiotics, put on a low-air-loss bed, and provided a nutritional consult and local wound care. The wound beds were free of necrosis but had copious yellowish drainage. A hydrofiber dressing was packed into the wounds twice daily and covered with a foam dressing. Ms. G's urinary incontinence made it difficult to keep her dressing intact. The foam secondary dressing was discontinued and replaced by dry gauze and a TAF over the hydrofiber. A plastic surgeon was reconsulted and after 1 week of antibiotics, NPWT was applied on the ischial wound with a good response. Ms. G was discharged but returned about 6 weeks later with another ischial wound infection. The same treatments (intravenous antibiotics, NPWT, and dietary supplements) were started and after several weeks, Ms. G was discharged to a long-term acute care facility for wound care. She did not like that facility and soon returned home.

After 1 month, Ms. G was readmitted to the author's hospital with another wound infection. She had not been using any dressings in her wound; she cleansed it daily and let it drain into her diaper. The need for dressings had been discussed with Ms. G's mother who reminded clinicians that her daughter insists on doing her own care and cannot be forced do anything against her will. During this admission, clinicians learned the patient had been sitting on the arm of her wheelchair to cook. A physical therapist and the author discussed the situation and initiated a search for assistive devices. Ultimately, plastic surgery was consulted and Ms. G was given a second myocutaneous flap to the inguinal wound, which partially dehisced and was treated with NPWT for several weeks. Eventually, Ms. G's numerous minor wounds all healed. Since this latest surgery and after several months in the author's facility, Ms. G has not been seen as an inpatient and has kept her appointments with the plastic surgeon. She has not availed herself of wheelchair clinic evaluation.

Conclusion

Care of the patient with a NTD requires a multidisciplinary approach and should begin early in the child's life. Education on preventing skin breakdown must be repetitive, frequent, and ongoing. Further research in the areas of nutrition and psychosocial issues in the life of a child with myelomeningocele is greatly needed.

Parents and medical professionals should approach local school districts and state legislators requesting early and serial testing of children with spina bifida for accurate placement in the school setting to maximize the child's learning abilities.

Research on venous congestion in this clientele also is needed. Minimizing the problems with access to care has the potential to greatly improve follow-up and follow-through.

It is vital for the global medical community to obtain and disseminate NTD prevention information to people planning to have children. Women who want to get pregnant or are in their childbearing years and may become pregnant should take either folic acid (400 micrograms) or a multivitamin with folic acid daily to reduce the risk of giving birth to a child with NTD.

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