CASE STUDY: Lymphedema In Spina Bifida

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I. Reason for Presenting Case Study

This case presentation of a 36-year-old female born with Spina Bifida resulting in bilateral lower extremity paraplegia highlights the importance of ongoing education of patient, family and physicians for edema management in this population. And, the need for a comprehensive long-term edema management plan that is realistic for individuals aging with a disability. Spina Bifida is the most common neural tube defect effecting 1/1000 births and more than 70,000 individuals in the U.S. It commonly results in lower extremity paralysis and hydrocephalus which may necessitate a shunt placement. Latex allergies and obesity are common. The effects of aging occur much earlier in this population and include skin thinning, decreased strength and flexibility, osteoarthritis, and osteoporosis. Urinary/bowel issues become more problematic. Recommendations for lower extremity edema typically include only limb elevation and use of compression garments.

II. Lymphedema Diagnosis

Patient is a 36-year-old, cognitively intact, wheelchair-bound female, who was born with Spina Bifida and bilateral lower extremity paraplegia. She was referred for lymphedema evaluation and treatment by her physician at the outpatient wound clinic where she was being treated for a stage III pressure ulcer on her right heel and a stage II ulcer on her left great toe. The heel ulcer had been present for the past 18 months. The heel ulcer resulted from static foot positioning on the footrest of her wheelchair. The non-healing toe wound resulted following removal of her toenail by her podiatrist for treatment of an ingrown toenail.

Patient presented for evaluation with her older sister who lives outside the home and accompanies her to most of her medical appointments. The patient had suffered from swelling of both legs and feet for the past ten years, which had exacerbated in the two years prior to our evaluation. Sensation in the legs was impaired from the buttocks to the knees, and absent from the knees distally. Both feet presented as “balloons” from the ankles distally. All toes were completely occluded on both feet by dorsal foot edema with the exception of the great toe on the left. This toe had been pushed medially and posteriorly by the swelling and had the appearance of being dislocated. 3+ pitting edema was present in both lower legs to the ankles. Edema at the ankles and feet was 3+/4+ and very firm. Soft, non-pitting edema was present from the knee to the groin on the right thigh.

Approximately one year ago, an attempt was made by her podiatrist to aspirate “the fluid” from the dorsum of her left foot. This was not successful and the patient developed an infected lesion at that location which ultimately took 4 months to heal. There was a circular scar 2 cm in diameter, in addition to significant thickening and fibrosis of the tissue in this area as a result of that procedure.

At evaluation, the total circumferential measurements (ankle to knee) was 113.1 cm on the right leg and 106.5 cm for the left leg. The circumferential measurements of the metatarsals on the right foot measured 33.5 cm and 41.2 cm on the left.
35.0 cm and 40.5 cm on the left. Significant time was spent in educating the patient and family concerning the commitment required for compression wrapping and the rationale that would ultimately lead to successful edema reduction and wound healing. Patient and her sister were enthused about finally finding some relief for this long-standing problem.

III. Other Medical Problems

Patient had three childhood spinal surgeries for scoliosis, a shunt placement at the right side of her head in 1998, a previous left hip fracture with pinning, and a right femoral fracture two months prior to the evaluation, for which no treatment was given. She also suffered from hypertension and acid reflux, had occasional pressure sores on her buttocks and weighed about 200 lbs.

IV. Psychosocial Problems

Patient attended school and a sheltered workshop until the age of 21. She lived with her parents and brother. Her father was her primary caregiver and was being treated for multiple myeloma and undergoing chemotherapy at the time of her evaluation. His health fluctuated throughout the course of her treatment. An older sister, not living in the home, tried to be present at her medical appointments and was the one who assisted the patient in communicating instructions to other family members. Teaching was done primarily with this sister, the father and another sister. Patient’s mother and brother were willing to assist, but never came for family training. In between treatment sessions, the patient would call the clinic with questions and concerns that other family members had regarding the treatment protocol.

V. Functional Limitations

Patient was dependent for transfers and had poor sitting balance. She had an electric wheelchair and a wheelchair van for community activities. Transfers in the clinic were maximum assist of two with a sliding board.

VI. Pain

Patient did not report pain due to insensate lower extremities.

VII. Degree of Impairment in ADLS

Patient was independent with hair care, minor hygiene and upper body dressing and was able to propel a manual wheelchair. She was incontinent of bowel and bladder, and dependant for transfers, lower body dressing and bathing. Patient was unable to perform pressure relief in her wheelchair. She utilized a Hoyer lift in the home.

VIII. Summary of Pre-Treatment Goals

1. Decrease edema;
2. Improve wound healing;
3. Education of patient/family for skin care and need for offloading at risk areas;
4. Recommendations for elevating leg rests on wheelchair to offload the right heel;
5. Develop realistic, long-term management plan that the family could carry out.

IX. Summary of Therapeutic Intervention

Patient was seen for a total of 29 visits from November 19, 2003, through February 16, 2004. Treatment consisted of MLD of both lower extremities and compression bandaging. Visits began at 3x per week, tapered to 2x per week and, ultimately, were 1x per week. This was beneficial as the patient was able to practice each aspect of her home program, get feedback from her therapist, and timely modifications were possible in order to better meet the needs of patient and family.

Visits 1-10 focused on education of patient, father and older sister in appropriate bandaging techniques, skin care, and precautions due to the insensitive nature of the lower legs. Patient tolerance for the bandages was good, but much repetition was required for family teaching, as well as to encourage the patient to be a more vocal director of how the bandages were to be applied. Bandage modifications were necessary to enable easier access to the wounds by the wound clinic. It became apparent that the bandages were not being removed on the days when patient was not in therapy. The need to assess the skin on a regular basis was addressed on an ongoing basis with patient and her sister. Planning for long-term management was initiated, including a thorough explanation of the use of non-elastic velcro band compression garments, bandaging, and utilization of a pneumatic compression pump.

Monochromatic infrared energy (MIRE) was initiated at visit 7 to enhance wound healing. Currently, MIRE has FDA approval only for diabetic ulcers, however, reports in the literature note beneficial effects on pain, wound healing and nerve function. The patient’s physician supported the use of MIRE in this case, although it was not reimbursable by insurance. Pads wrapped in plastic wrap were applied directly over the wound beds. Intensity was set at 6 bars for 20-30 minutes 3x per week. Results were very dramatic in that at visit 11, the toe wound was completely closed and the heel wound was improved by 50% and totally closed at visit 19.

Visits 12 through 19 focused on the softening of fibrotic tissue in the feet through the use of foam, chip bags, etc., at the foot and ankle, ongoing instruction in skin care and modification of bandaging to address the new shape of the foot and ankle. During this time, patient developed some blisters from lack of removing the bandages. These were addressed and resolved in a timely manner. Patient chose a 3 velcro band non-elastic compression garment as the easiest for her caregivers to manage in the home. These garments were received on visit 20 and instructions were given to the patient and her sister. A long stretch bandage was substituted for the ankle foot wrap in order to provide better control over the swelling at the dorsum of the foot.

Visits 21 — 29 focused on repeated instructions in an appropriate donning and wearing schedule for the non-elastic velcro garments and compression.
bandaging of the foot. Patient was issued a skin inspection mirror for her feet. The importance of skin care was stressed once again. Patient received a pneumatic compression pump for home use as a means to prevent further lymph and venous stasis after discharge. She was instructed in self MLD to be performed prior to and during pump application. The pump was set at 45mmHG, with both legs treated simultaneously. Discharge instructions on visit 29 were to wear the non-elastic velcro garments during the day, leave the legs free of compression at night and to use the pump on a daily basis (with self MLD) for at least one hour at a time convenient for the family.

X. Treatment Outcome: Goals Achieved/Modified

At discharge, the pitting edema was resolved; the tissue quality throughout both lower extremities and feet was much improved. A minimal amount of fibrotic tissue remained on the dorsum of the left foot. Overall, total circumferential measurements of the leg, measured from the ankle to the knee on the right, decreased from 113.1cm to 85.9cm, and from 106.5cm to 92.3cm on the left. The total circumferential measurements (metatarsals + arch) of the right foot at evaluation was 68.5cm on the right and 81.2cm on the left. At discharge, the total foot measurements were 40.7cm on the right and 46.8cm on the left. Wound closure was 100% on all wounds. Patient and family demonstrated independence in use of the non-elastic velcro garments, intermittent bandaging, skin care and understanding of the use of the pneumatic compression pump. The patient was discharged with skin intact, edema stable and recommendations to attempt offloading of her heels through elevating leg rests or other means.

XI. Follow-Up

Patient was seen for three follow up visits between 3/29/04 and 6/24/04. Her father’s cancer exacerbated in April and he passed away in June. These months were a chaotic and stressful time for the entire family, making it difficult for consistency with the home program that had been set up at discharge. She had additional visits to the wound clinic and with us. Edema reduction had been well maintained, but she had ongoing issues with skin breakdown, an infection in her right foot and an allergic reaction to medication. At this time, her edema was stable and wounds once again were healed.

She now had an outside daily caregiver who assisted her with self care, checked her skin, and assisted with her edema management program, including donning the non-elastic velcro band garments, intermittent bandaging and pump use on regular basis. We remained available for support as needed.

XII. Conclusion

Individuals with Spina Bifida may have longstanding edema that has never been addressed successfully. In this case, MLD/CDT was successful in resolution of longstanding edema; skin health was improved; patient’s self esteem was enhanced. Use of monochromatic infrared energy (MIRE) to enhance wound healing in conjunction with MLD/CDT was instrumental in rapid wound healing, resulting in fewer therapy visits and decreased risk of infection. Despite providing this patient and her family with all the tools for a comprehensive home program, keep in mind that these tools are given at one point in time. LE therapists must remain available over time to address the changing needs and circumstances of our patients.

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