Cover Story

The Special Challenges of Hemipelvectomy and Hip Disarticulation Patients

by Rachel Kelley

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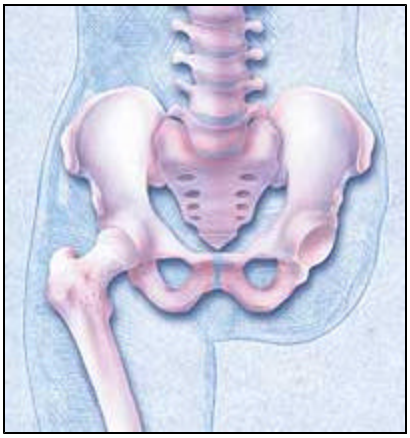

Hemipelvectomy (HP) and hip disarticulation (HD) patients are rare within the amputee population. Generally, prosthetists will see maybe one or two in their professional career and the health care community, including physicians, physical therapists and psychologists, has little or no experience treating them.

Interestingly enough, three of the health care professionals interviewed for this article are high-level amputees. *O&P Business News* highlights some of the challenges for high-level amputees, as well as recommendations to patients and clinicians. Topics include how to find the right prosthetist, prosthetic options, walking and sitting with a prosthesis, rehabilitation and exercise, psychological intervention, sexual issues and assistive devices.

Statistics

While statistics on HP and HD are scarce, the latest numbers available from Johns Hopkins University School of Medicine, Department of Public Health, and the National Limb Loss Information Center in conjunction with the Amputee Coalition of America, reported 4,698 new HDs and 1,890 new HPs from the years 1988-1996. According to Christina Skoski, MD, a physician specializing in clinical anesthesia at Huntington Beach Hospital, Huntington Beach, Ca., and a hemipelvectomy amputee, the statistics do not consider the number of people who do not survive because of their cancer or those people who had their amputation before 1988 and survived. Skoski added that the number of high-level amputations are decreasing with time because of more effective cancer treatments and limb salvage procedures.

“Bottom line is we do know it is extremely rare and most people say HPs and HDs represent approximately one percent of all amputations in the United States,” said Skoski.

Common Reasons

The most common reason for an HD or HP is a rare form of connective tissue cancer known as sarcoma. There are various types of sarcomas such as fibrosarcoma, osteosarcoma and chondrosarcoma. Generally, in an HD patient, the leg is removed at the hip joint and the pelvis and its associated muscles are left intact. In an HP patient, the leg, hip joint and half of the pelvis are removed, and the remaining gluteal muscles are brought around and attached to the oblique abdominal muscles. Skoski said that what separates the HD and HP amputees from other levels is they do not have a functioning hip to activate a prosthesis.

“It becomes infinitely more difficult to walk with a prosthesis and simply sit when you are missing that third functional joint, which is the hip,” she said.

Getting Up and Sitting

Simply getting up off the floor can be an arduous undertaking.

Mary Witt, PT, of Vail Valley Medical Center Home Health, Vail, Colo., and a hemipelvectomy amputee, said getting up off the floor is a real challenge because of the length of the prosthesis and the joints involved.

Michael Clapp, CPO, of Scope Prosthetics and Orthotics, Orange, Ca., agreed.

“To help with this problem, we try our best to make sure the height of the prosthesis is just right, adjust how much the person collapses into the socket and place the foot correctly. Alignment is an issue, so we make sure the patient is safe and they don’t fall,” he said.

For both the HP and HD patient, sitting can be a challenge. The HP has no ischium and the HD is sitting directly on the ischium, which can be very uncomfortable.

“The HP patient has no pelvis,” said Skoski. “We cannot sit up straight. If you try to sit us up straight, we tilt and fall over like a doll.”

Skoski said a wedge, pelvic leveler, sitting socket or something firm can be placed underneath to take the place of the pelvis. Clapp added that the size of the patient, how the socket fits and how high the socket comes up determine how straight an individual can sit.

“If the socket comes up too high, the person may lean to one side so we have to build up underneath the amputated side to level them out,” he said.

Postoperatively, patients are often advised not to sit because they would be sitting directly on their incisions.

“In order to allow time for the wounds to heal, the area needs to free of any pressure,” said Skoski. “This is why they have tilt tables and special beds and mattresses.”

Walking With a Prosthesis

For a high-level amputee, the energy requirements to use a prosthesis have been reported to be as much as 200 percent of normal ambulation. Only a small percentage of people become long-term wearers.

Sandra Houston, PhD, a clinical psychologist, hip disarticulation amputee and retired professor who teaches part time at Rollins College, Winter Park, Fla., explained that because there is no residual limb on high-level amputees, there is more mental energy required to ambulate. Whereas non-amputees walk with closed loop sensory feedback, an HD/HP patient must use secondary sensory information from other sense organs. This extra energy requirement results in less available mental energy for enjoyment of their surroundings.

“A high-level amputee must constantly pay attention to the prosthesis and how they are walking. It requires a lot more secondary sensory information and they get fatigued rather quickly,” she said.

Tony van der Waarde, CP(c), and John Michael, MEd, CPO, in the *Atlas of Limb Prosthetics: Surgical, Prosthetic and Rehabilitation Principles*, wrote that prosthetic fitting in high-level amputees is typically limited to motivated and physiologically vigorous individuals.

“Many people are not happy wearing a prosthesis because of the fit, the energy requirements or because they are not willing or able to make it work,” said Witt. “In part, it’s a personality type. To be successful wearing a prosthesis, you have to be really stubborn and determined.”

Challenges of Prosthetic Fitting

It can be difficult for a prosthetist to fit a high-level amputee. The lack of a hip joint makes it almost impossible to activate a prosthesis. It takes patience on the part of the prosthetist and patient to get a proper fit. It can also be expensive. The major challenge is getting the socket to fit well.

“The most important aspects of making a prosthesis are getting a good socket fit, keeping it as low profile as possible and at the same time containing all the tissue and preventing the patient from sliding out of it,” said Clapp. “The key is the materials — the flexible bioelastics, plastics and resins.”

Clapp said that the socket is like a bucket that the patient has to get into. Somehow it has to be opened up enough for them to slide into. Depending on how rigid the materials and frame are, you can open it up in the back, front or side.

“I typically open it up in the front,” he said. “With the more flexible resins, it’s easier to have just a single opening.”

“In years gone by, the only material that was available was the hard, laminated plastic,” Skoski added. “I had that for many years and it broke my ribs.”

The objective is to get the patient as comfortable and functional as possible.

Witt agreed that fit is crucial. She recommends that the prosthetist bring the socket all the way up to the patient’s lowest ribs. Some patients, she said, want it to be lower, but she believes that’s a mistake because the lower back is not supported and the tissue is not contained.

“Even if it’s a softer material that goes up higher, it’s important to do,” she said.

Some people will also have a strap over the shoulder for extra support. Skoski reminds new patients that it is usually the first leg that is the worst, because you do not know what to expect yet.

“The prosthetist has to start somewhere,” she said. “Start with the first one and go from there. You’ll find what you like and don’t like.”

Assessing the Quality of Life After Amputation or Limb Salvage

According to a study in *Clinical Orthopaedics and Related Research*, patients with amputations, including hemipelvectomy and hip disarticulation patients, do just as well in terms of life adjustment, and in some cases better, than patients who have had limb-saving procedures.

Researchers reported that the two groups walk equally well, although amputees have more need for walking aids. The difference in the groups’ employment status and participation in sports were statistically insignificant. Both groups have an equal number of marriages and satisfactory sexual lives, and the psychological adjustment to surgery was equal in both groups with a small number experiencing anxiety, depression, insomnia or need for medications.

The significant differences of the study were the ability to have children after surgery and the experience of amenorrhea. Fifty-two percent of the 23 patients with amputations had children after their surgeries, whereas 19 percent of the 140 limb-sparing patients had either sired or borne a child. About one-half of the women with amputations had normal menstrual periods compared with less than one-fourth of the women with limb-sparing procedures. The authors noted that the variation in these statistically significant findings may be due to the amount of time since the surgery for each group — 12 years for the patients who had amputations and seven years for the patients who had limb-sparing surgery. They hypothesize that the amputee patients could have received less chemotherapy than the limb-sparing group. Therefore, the patients with amputations had less interference with menstruation and lower rates of sterility.

The study concluded that amputation is not the terrible ordeal it was once thought of as being. Patients who had amputations reported as much satisfaction, competency and psychological adjustment as patients who had limb-sparing surgery.

For more information:

Refaat Y, Gunnoe BS, Hornicek F, Mankin H. Comparison of quality of life after amputation or limb salvage. *Clinical Orthopaedics and Related Research*. 2002;397:298-305.

Time to Heal

Skoski believes that all too often, high-level amputees are not given enough time after surgery to heal before a prescription for a prosthesis is given. She noted that patients are sent home too soon and with a minimal amount of physical therapy and little or no physical conditioning. They do not have enough stamina, strength or balance to use a prosthesis.

“There are people who cannot even stand on one leg who think they can just put a leg on and walk,” she said. “Even if they are in superb physical shape, it is still going to take anywhere from six months to a year before they can be a good walker.”

She also said that many sarcoma patients may go through several rounds of chemotherapy, radiation or both before or after surgery, which significantly reduces strength.

“Most people have been in a hospital bed for weeks if not longer,” she said. “They are weak and predictably deconditioned.”

Rehabilitation and Conditioning

It is critical, said Clapp, that patients learn how to maneuver around the house, in and out of a car and up and down ramps and stairs. In order to perform these activities, the importance of physical fitness cannot be overstated. Houston added that what she hopes the prosthetist understands is that if a person is inactive before the amputation, he or she will likely be inactive after. But if the person was an athlete, goals and expectations will be different.

“Rehabilitation and conditioning goals need to be adjusted to the individual patient,” she said.

Witt emphasizes conditioning the patient within his or her limits prior to and after surgery.

“This means cardiovascular and strengthening exercises,” she said. “Abdominal exercises are particularly important because we use the abdominal muscles to propel the prosthesis.”

Skoski said that strength training is crucial to prevent osteoporosis. An HD or HP patient is more

likely to break bones because of more frequent falls. A referral for an exercise program from a physician should be instituted as well.

Choosing a Prosthetist

As stated, most prosthetists have little experience in fitting high-level amputees. A most important attribute is patience.

“The prosthetist needs to be able to listen to the patient,” said Skoski. “They must be willing to go back to the drawing board and do it again and again until they get it to fit comfortably.”

Houston said that the prosthetist is in a double bind because he or she wants the patient to get back to all the activities they could do before the amputation, but at the same time, he or she does not want to present unrealistic expectations. Clapp agrees.

“The high-level amputees are probably the most challenging patients we treat,” he said. “We have to be a little bit of a psychologist, learn what their wants and goals are and treat each one individually. There is a business side to it also. You can’t always give them everything they want, but we try.”

Assistive Devices and Scolosis

There are several options to choose from in terms of assistive devices and many amputees choose to use them in conjunction with, or instead of, a prosthesis. Skoski said that once the leg is taken off, crutches are often used. Others prefer wheelchairs or scooters.

“The patient should not be pushed by their doctor, husband, wife, parent, prosthetist or physical therapist into choosing a particular device,” she said. “Plus, it is not a good idea to get locked into using only one. Experiment with different devices and choose the ones that meet the most needs.”

In order to avoid scoliosis, Witt said the back must be straight before the patient is casted.

“If the back is not straight, they’re casting the patient with a scoliosis, which will be supported and stay there,” she said.

The development of scoliosis is a combination of anatomical alterations due to the surgery and incorrect body mechanics.

“With the removal of one half of the pelvis, the normal attachments of muscles and tendons between the lower back and pelvis are lost,” said Skoski. “The muscular forces holding the back straight are now uneven, she said, and in order for the patient to sit upright, they will automatically shift their weight to the sound side, tilting the sacrum.” Also contributing to scoliosis, she said, is the shifting of the body to one side while on crutches, uneven gait in the prosthetic user due to the prosthesis being made intentionally shorter to assist swing phase, and abnormal gait because of excessive forces placed lower back to propel the prosthesis.

Psychological Aspects

According to Houston, there is no difference in psychological adjustment between high-level amputees and other amputees. Most are well adjusted and lead fulfilling lives. There are some additional challenges for the high-level amputee. Psychological adjustment significantly correlates

with the extent to which an individual reports whether their activities are restricted. When activities that are essential to an individual's identity and self worth (self care, other care, recreation and relationships) are threatened, they may feel demoralized and become depressed, Houston said.

"It depends on their premorbid adjustment," said Houston. "If they were a psychologically healthy person before the amputation, they will be afterwards."

High-level amputees do have to contend with unrealistic expectations that are imposed upon them by society, family and even themselves. Houston said that the media, for example, will present amputees climbing mountains or other athletic endeavors with their new, high tech leg.

"For the high-level amputee, most of the technology doesn't work because there is no residual limb and in HPs, there is no hip," said Houston. "These disappointments can be overwhelming and depressing at times."

Additionally, many transtibial and transfemoral amputees are able to walk without anyone knowing they are an amputee. High-level amputees will always walk with a limp, so people will know they are disabled or different. Because of this, social stigma is often present. Houston said high-level amputees are more dependent than other amputees, and this can be a blow to high achievers.

"Their greatest fear is that they are going to lose their other leg due to the cancer coming back," Houston said. "In terms of counseling, they need to go through the grieving process and eventually accept what is realistic."

Unfortunately, sometimes people will stare and ask the high-level amputee intrusive, insensitive questions.

"The amputee is sensitive to others' reactions and becomes more sensitive over time. The amputee must learn not to personalize these negative biases held by the public."

Sex, Body Image and Other Issues

Skoski said that depending on what has been damaged and how much tissue was resected, there may be alterations in urination, defecation and sex.

"The ability to urinate or defecate normally depends on whether or not nerves have been damaged or removed," she said. "Occasionally, the tumors have invaded the colon so the patient may need to have a colostomy. Self-catheterization may be necessary for urination."

Constipation and dehydration may also be a problem due to excessive sweating.

There may be a weakened pelvic floor, at least on one side, which can make sexual relations difficult or painful for women. Sex often requires some modifications. Skoski recommends talking to a gynecologist and possibly a physical therapist to learn pelvic floor exercises.

Body image concerns are significant.

"They have a unique situation of having three body images — one with the prosthesis, one without the prosthesis, and the pre-amputation, intact body," said Houston.

For a high-level amputee, issues surrounding sex and body image can be discussed with a psychologist who specializes in sex therapy. Houston said that many amputees will unnecessarily return to the prosthetist because he or she is the only one who is touching them. Sometimes the

person simply needs assistance in meeting the need for touch through family and friends rather than in a sexual encounter.

“During sexual relations, instead of focusing on what is not there, they need to focus on what is there,” said Houston.

Often, whether the person is married, single, young or older determines how sex will be viewed. Cosmesis depends on age, too. Older amputees are generally more accepting whereas younger ones place more emphasis on appearance.

“As in any trauma, they must reassess their relationship,” she said. “The majority of high-level amputees are well adjusted and have come to see their amputation not as a defining characteristic, but as one of many challenges faced in their lives.”

For more information:

- van der Waarde T, Michael JW. Hip disarticulation: prosthetic management. In: JH Bowker and JW Michael, eds. *Atlas of Limb Prosthetics: Surgical, Prosthetic and Rehabilitation Principles.* 2nd ed. St. Louis, Mo: Mosby-Year Book; 1992.
- www.awardprosthetics.com/disartic/disartic.html
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