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## Cover Story

February 1, 2007

### Living With the Ghost: An Update on Phantom Limb Pain

**Studies suggest that up to 80% of amputees will experience phantom pain in their lifetime. With few questions answered, patients and practitioners find their own ways of handling the agonizing affliction.**

By Jennifer Hoydicz

Phantom limb pain is a phenomenon that has baffled the minds of both health care experts and patients for centuries. In a profession where seeing is believing, there is much to be discovered about the absent agony that many amputees will experience in their lifetimes.

According to "Phantom Limb: From Medical Knowledge to Folk Wisdom and Back," published in the *Annals of Internal Medicine* written by James Herman, MD, the first recognition of post amputation pain was allegedly in 1551 by Ambroise Pare, a military surgeon of the 16th century. Phantom limb pain is also referenced in some of the most widely read literature of all time, including *Moby Dick*.

So, why has there been so much mystery for so long?

Putting the obscurity of the phenomenon aside, phantom limb pain sufferers are often afraid to come forward, fearing that they will be stigmatized or labeled as 'crazy.' While recent surveys and research may not have all the answers, these studies do come to one common conclusion – phantom limb pain is a real medical mystery that a majority of amputees will deal with at one time or another.

#### Recognizing the signs

"Phantom limb pain seems to be more intense in the perceived distal portion of the phantom, may be related to its perceived position or movement and can have a number of characteristics such as stabbing, throbbing, burning or cramping," Cheree Nichole, MA, president of Prosthetic

Science Houston Inc. Research Division told *O&P Business News*.

Other common patient descriptions of phantom limb pain are tingling, squeezing and shooting pain. Additionally, each patient has a unique pattern of episodes that could have few to no commonalities. The types and levels of pain promise that no patients are alike, making methods of proper treatment difficult to decide.

Phantom limb pain is sporadic and unpredictable in the way it can affect the individuals who suffer from it.

Trying to dig deeper into the severity of the episodes and the exact location and feeling can only help when it comes time to decide on treatment. But first it is important to make sure you are addressing the correct problem.

Listen closely to your patients' descriptions of pain in order to determine whether they are truly experiencing phantom limb pain or another associated feeling such as phantom limb sensation or residual limb pain.

### **Other ailments to watch**

Oftentimes, phantom limb pain is mistaken for residual limb pain or phantom sensation. Given the similarities between them, it is understandable.



### **Residual limb pain**

Residual limb pain is exactly what it sounds like – pain in the remainder of the existing limb. The good news is that this kind of pain can often be treated, although no treatment is guaranteed. Patients need to be aware, however, that it is normal for their residual limb to be more sensitive than other areas of their body.

Sometimes residual limb pain is caused by prosthetic fit. Often when patients are experiencing added pressure on the residual limb, it can be alleviated with a new fitting or change of padding.

Surgery may be necessary to revise an amputation in cases where excessive scar tissue or nerve damage is noted.

The key to diagnosing residual limb pain is to see if your patients describe what seems like muscle pain, pressure or joint pain. This becomes of special importance as your patients age and their prosthetic needs change.

### **Non-painful phantom sensation**

Phantom sensation differs from phantom pain in one important area. Sensations, while they can feel like itching, warmth or cold, are not unpleasant. These feelings are often not disabling, as phantom pain can often be. Sensations do not need to be treated until or unless they become painful.

### **Phantom limb pain**

“Pain in the phantom is a sensation which appears to come from the part of the limb which is missing,” Richard Sherman, PhD, director of the Behavioral Medicine Research and Training Foundation and dean of clinical psychophysiology at the University of Natural Medicine said.

Sherman has found through his research that certain pains are caused by physical ailments.

“Burning pain can be caused by poor blood flow in the residual limb,” he said. “Similarly, cramping pain can be caused by cramping in the residual limb.”

Phantom limb pain can vary in intensity from patient to patient. Treatments vary along with severity. There are a series of surgical, non-surgical and psychological treatments that can provide relief for some patients.

### **Factors to consider**

Sherman said that many amputation factors seem to make little to no impact on the degree of phantom limb pain. However, he and Nichole agree that age has a strong correlation with phantom limb pain.

“As you get older, your vascular system does not function as effectively so if you already have compromised circulation of the residual limb, you will have even more compromised circulation,” Sherman explained. “As people get older, they tend to have more burning and tingling sensation in the residual limb and those feelings are often transferred into the phantom.”

Nichole agreed and added that most of her work has been with older patients with diabetes and her research shows a high prevalence of older amputees with phantom limb pain.

“Patients who have vascular complications due to diabetes are 46 times more likely to have a lower limb amputation than non-diabetics,” she said.

Also, Nichole believes an even stronger correlation can be found between pre-amputation pain and phantom limb pain.

“Chronic pain before amputation is an important predictor of later phantom limb pain and is related to frequency, type and severity of phantom limb pain in up to 79% of patients,” Nichole said.

Nichole also said there is strong evidence to support the fact that phantom limb pain is more prevalent in the cases of certain types of amputation, stating that it is more common in transfemoral amputations and least common in congenital cases. Also, in trauma related amputation, she said that patients report a pain similar to trauma pain.

Sherman did not agree. His research showed that these factors do not play a role in the prevalence of phantom limb pain.

### **Theories about the origin of phantom limb pain**

Phantom limb pain is classified as neuropathic which, unlike nociceptive pain which is an adaptation that serves to protect an organism from injury, does not have the same protective value, Nichole explained.

Common patient descriptions of phantom limb pain are tingling, squeezing and shooting pain. Phantom limb pain is sporadic and unpredictable in the way it can affect the individuals who suffer from it.



A variety of theories have been proposed to explain the origin of phantom limb pain including peripheral, central and cortical changes. Each theory published has studies that both support and counteract their concepts.

#### **Peripheral changes**

Often neuromas can form on the nerve endings of the residual limb following amputation.

“Neuromas generate abnormal ectopic activity which increase residual limb pain and phantom limb pain,” Nichole said. “For example, some patients report that if they tap, touch or rub the neuroma, it will cause phantom limb pain.”

Practitioners will often instruct patients to massage the residual limb or apply hot or cold therapy.

Nichole explained that a study was conducted that attempted to put a nerve block in place to interrupt the sensory pathways and end phantom limb pain.

“The interesting thing about the peripheral theories of phantom limb pain is that while anesthetic blocks of neuromas did eliminate residual limb pain, it did not eliminate ongoing phantom limb pain,” Nichole said. “Moreover, phantom limb pain is often present soon after amputation and before a neuroma could have formed. As a result of these and related findings, research began to focus on ectopic activity more proximal to the residual limb as a potential etiologic factor of phantom limb pain.”

### **Central changes**

“Some researchers have focused on ectopic activity more proximal to the residual limb such as that occurring in the spinal cord called central sensitization,” Nichole said.

Intense or persistent residual limb pain and catastrophizing the pain experience itself can lead to hyperexcitability of the spinal cord, a reduction in inhibitory processes, and nerve changes, which then amplify subsequent pain, Nichole explained.

Research using spinal anesthesia intended to block the added input and lessen hyperexcitability have not had a measurable impact on reducing phantom limb pain.

### **Cortical changes**

The primary somatosensory cortex is the area of the brain responsible for pain processing.

Nichole found that when patients experience pre-amputation pain, “there is an expansion of the representation zone of the painful stimuli and the somatosensory cortex increases the sensitivity to pain.

“Subsequent to amputation, when somatosensory input from an amputated limb ceases, brain areas (now enlarged) which normally represented the painful limb before amputation are functionally taken over by the migration of neighboring somatosensory reception sites into these vacant areas devoted to painful stimuli,” Nichole said.

Nichole’s research noted that the larger the shift, the greater the phantom limb pain.

## Talking to Your Patients

Prosthetists and their patients share a closeness that is special to the field of prosthetics. Building friendships and working relationships requires unvarying open communication, excellent listening skills and an encouraging attitude. Prosthetists can help their patients by maintaining that relationship and making them more comfortable with issues that may seem most worrisome.

### **Open the lines of communication**

The subject of phantom limb pain is a familiar one to prosthetists. It is essential to keep in mind that your patients may not be as well informed. For that reason, it is important that you bring up the subject to make them more comfortable confronting it.

While the days of shunning members of society for their phantom pains seem long gone, it is important to keep your patient pool in mind. Many older people are dealing with amputation, and they might be less likely to speak up about phantom limb pain.

### **Listen to their concerns**

Listening seems like an obvious thing to do when meeting with your patients, but when it comes to phantom limb pain, listening to their concerns is essential. Making sure to understand the pain they are feeling to correctly address it is vital in restoring your patient's ability to carry out everyday functions. Given all of the mystery that still surrounds this age-old topic, you can never be too cautious in diagnosing the problem.

Also, be sure to follow up with your patients about the path of treatment they are on. What works for some does not always work for all, and oftentimes treatments need to be revisited and changed to maintain their success.

### **Encourage them to use available resources**

The phenomenon strikes individuals differently, but it is important to remind your patients that they are not alone. Approximately 80% of amputees will experience phantom limb pain at some point in their lives. Encourage them to do some research and seek out groups online for support. It might help to talk to others in the same situation.

### **Treatment options**

To date, there is no cure for phantom limb pain. Also, no treatment has been developed that can be prescribed to amputees across the board. Methods that work for some people, fail entirely for others. Also, methods that once worked for some patients can stop having the same positive effects after a period of time.

It is important to encourage patients to recognize their personal triggers of phantom limb pain. This will help both prosthetist and patient in deciding on appropriate treatment. Triggers can include prosthetic fit, pressure on the residual limb, catastrophizing, stress and fatigue.

### **Non-surgical options**

Medications that are commonly prescribed for chronic pain are frequently used in the treatment of phantom limb pain. Transcutaneous electric nerve stimulation, also known as TENS, is commonly used to decrease pain perception. This technique intends to control chronic pain by a process that sends electrical current to specific nerves, which generate heat to relieve pain.

A nerve block, which is the injection of a local anesthetic into a nerve, is used to interrupt pain sensory pathways and prevent them from reaching the brain.

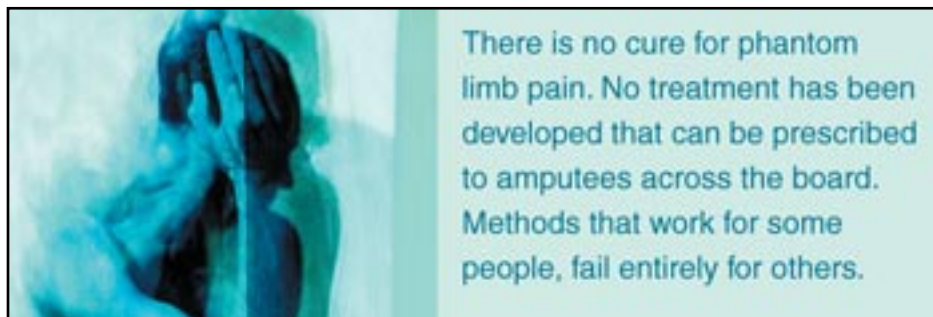
Farabloc fabric has also proven to be an effective tool in combating phantom limb pains. The fine stainless steel fibers embedded in nylon allow for better blood circulation.

Acupuncture has been successful in lessening the effects of chronic pain. It is said to stimulate the nervous system to release natural pain relievers.

### **Surgical and psychological options**

Spinal cord stimulation is a procedure during which electrodes are placed along the spinal cord to relieve pain. Deep brain stimulation is similar to spinal cord stimulation except the current is distributed to the brain. Intrathecal drug delivery allows for pain medication to be concentrated directly into the spinal fluid by way of an infusion pump and an intraspinal catheter.

In the past, hypnosis has been effective for some patients in lessening the occurrence of phantom limb pain. This requires that the patient be relaxed and able to receive suggestions that aim to lessen pain perception.



Biofeedback teaches the patient how to regulate body functions such as body temperature and blood pressure, which could be triggers for phantom limb pain.

"For cramping phantom pain, the best intervention is biofeedback," Sherman said.

Physical therapists or psychologists who are experts in muscle tension biofeedback can help to stop the spasms that patients feel, he continued.

"Right now we are chasing phantom limb pain," Nichole said, "Our interventions are happening after our patients identify they are having phantom limb pain."

Currently working on new psychological approaches, Nichole hopes to eventually make phantom limb pain more preventable through pre-amputation measures when applicable. Her studies are still underway.

**For more information:**

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Jennifer Hoydicz is a staff writer for *O&P Business News*.

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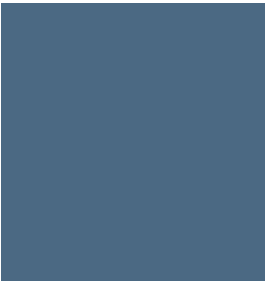
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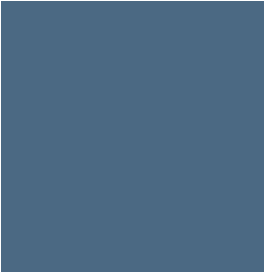
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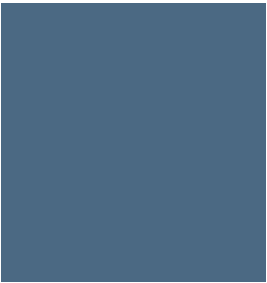
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