

Rehabilitation

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Health care providers can help those with SCI—and their partners—overcome some common obstacles

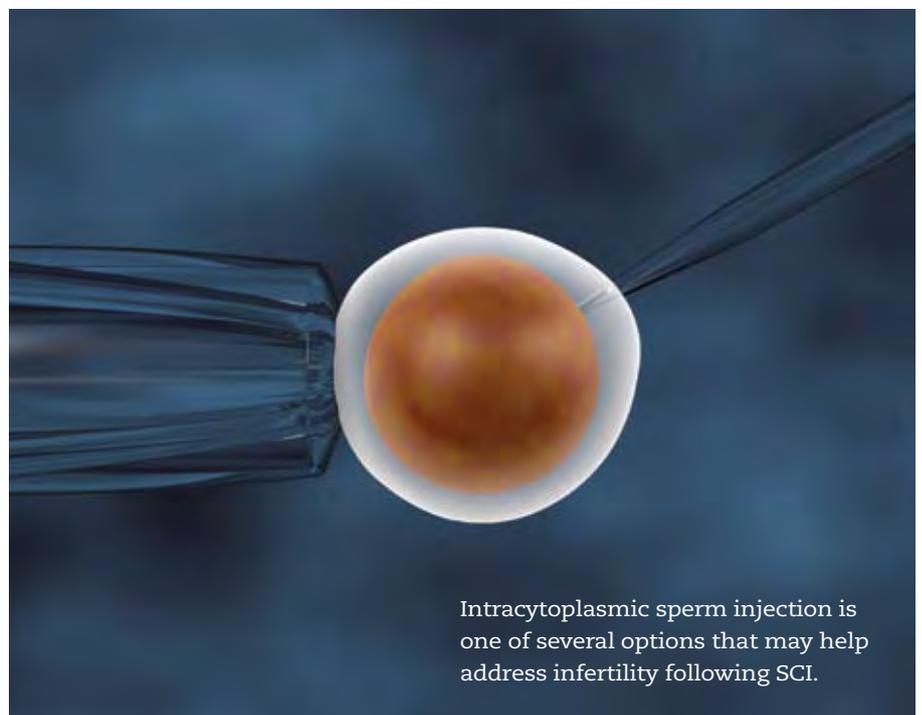
■ TODD A. LINSENMEYER, M.D.

Individuals with a spinal cord injury (SCI) face many challenges, including issues related to sexuality. SCI usually results in tetraplegia (80 percent of cases) rather than paraplegia (20 percent). The typical person who suffers an SCI is of prime reproductive age, and sexuality is a key concern for the vast majority of these patients. In one study, persons with paraplegia rated sexual function as the number one priority among all functions, including walking and bladder and bowel function. Those with tetraplegia rated it number two, after hand and arm function.

Some of the issues that impact sexuality for both men and women with SCI include changes in body image, reduced mobility, spasticity, difficulty with positioning during intercourse, and possible bowel and bladder incontinence. Individuals also have challenges unique to their genders.

Women's Issues

Until recently, many studies have ignored women's post SCI sexual function. Women with SCI experience normal changes above the level of injury, including "skin flush" and changes in the (continued on page 7)



Intracytoplasmic sperm injection is one of several options that may help address infertility following SCI.

FOCUS ON

Rehabilitation

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True Love for Medical Rehabilitation

Not many people talk about love and rehabilitation in the same breath, yet love in its many forms attracts providers to the rehabilitation field and enables the success of our patients.

Physical Medicine and Rehabilitation (PM&R) is filled with professionals who are absolutely passionate about their careers and exhibit a remarkable enthusiasm and energy; and most people enter PM&R because of some type of love. They may feel the unique sense of compassion that comes from caring for a relative with a disability, or perhaps have a great desire to study the human body's mechanical intricacies. Maybe they simply experience fulfillment in helping others to help themselves, or in establishing long-term relationships with patients and their families.

I have observed that love is also essential to healing for many of our patients. A person may progress better in his or her rehabilitation program if loved ones provide support throughout the hospital stay and upon return home. And, sometimes it takes love to be able to achieve real independence. Consider the following two stories. Although the names have been changed, they are brief but true accounts of the power of caring.

John happened to be walking by a hospital emergency department in Boston when he was shot in the neck. He survived only because he was literally at the hospital's doorstep when this happened, but he became a ventilator-dependent tetraplegic. The young man was admitted to a rehabilitation unit at that hospital and received excellent care, yet he could not be discharged because he had no place to go. John had no family willing to help, and he lacked health insurance; no nursing home would take him, and he continued to live at the rehabilitation hospital for the next 10 years.

Then one of the unit's secretaries fell in love with John, and his life changed again. They decided to live together, and he was able to move into a home with her. Love was the reason John was finally discharged.

Sandra was born prematurely with bronchopulmonary dysplasia (BPD), a condition in which the baby's lungs are inadequately mature at birth and cannot support respiration. Although a baby with BPD may outgrow dependency on a ventilator as his or her lungs grow, the process can take a few years. Unfortunately, Sandra's mother abandoned her soon after birth. With no other family, the child was essentially an orphan.

Then love intervened. One of the nurses who had been caring for her in the pediatric rehabilitation unit developed a profound affection for Sandra, adopted her and took her home. The moral of Sandra's story, like John's, is simple: Sometimes it just takes love to bring about a wondrous transformation.

Love is an important part of our professional satisfaction and our patient successes, and often it is this emotional connection that can make all the difference in the world in terms of living your life to the fullest.

A handwritten signature in black ink that reads "Bruce M. Gans, MD". The signature is written in a cursive, flowing style.

Bruce M. Gans, M.D.
Chief Medical Officer



Taking a Step Forward

With recent advances in prosthetic designs, patients and their clinicians have many choices

■ JOSEPH G. REDA, CPO, LPO-NJ

Given the impressive array of scientific breakthroughs in our times, it is not surprising that sophisticated technology now permeates the world of foot and ankle prostheses. The past decade has seen significant progress as manufacturers have applied innovations in materials and design to accommodate the diverse lifestyle needs of users. For the patient, this translates into a more normal gait, often an enhanced natural silhouette, and the potential to participate in a greater range of activities, up to and including competitive running.

But how do rehabilitation specialists determine which kind of prosthesis is appropriate for a particular patient? Typically, clinical decisions drive the choice of technology, with higher-functioning users receiving more advanced products that meet the needs of their increased activity levels. In fact, prosthetic designs are grouped around Medicare's Functional Level System, which categorizes patients from K0 to K4, with K0 meaning in a wheelchair and K4 representing the highest level of activity.

Choices, Choices

For those in the lower functional levels, in which there is little need for lateral

movement, the simple and supportive Solid Ankle Cushion Heel (SACH) foot is appropriate. Moving up the scale, a unit that is articulated—such as one of the multi-axial College Park feet—allows for a significant range of motion in multiple planes. These units provide a cost-effective alternative for patients who require greater mobility, although they do not incorporate the motion-sensor technologies found in more expensive designs.

For athletes, there is the so-called “sprinter leg,” which is a carbon graphite lower leg and foot prosthesis designed specifically for sprinting or running. The device helps store and return energy, and also gives the user a feeling of pushing off. The trade names say it all: the Cheetah, Flex Spring, Flex Run. The more functional appearance is not an issue because the emphasis is on high-performance. Although these prostheses are effective for running, which emphasizes toe contact with the ground, they are not realistic for everyday walking because they lack a heel component.

Enter the Computer Age

The Rolls Royce of prosthetic feet is the Proprio, manufactured in Iceland by Ossur. This elegantly designed carbon foot closely approaches the

performance of the human foot through integrated artificial intelligence. Kessler Institute for Rehabilitation is one of the first hospitals in the nation to make the Proprio available to patients.

The unit allows a person to walk more comfortably on level ground and on changing terrain, including slopes and even stairs. Individuals can sit and stand more naturally, as well. And, unlike the traditional simple prosthetic foot that was locked at a 90-degree angle, the Proprio plantar flexes to a resting state of about 15 degrees.

Because the Proprio's technology is so new, insurance companies are reluctant to cover it. Prosthetic feet in general can be expensive—with a below-the-knee prosthesis, the cost of the Proprio is about \$30,000. Typically, workers' compensation insurance companies will reimburse the expense because the employee is able to return to the job as quickly as possible. Medicare and Medicaid, as well as major medical insurance companies, do not currently cover the cost except in rare cases.

There Are Limits

The Proprio device has its shortcomings. It requires a large battery pack, and the mechanical heel has to remain exposed. Indeed, the user is walking on a computer, and in the long term, it's not going to withstand the stresses of running, nor will it take the constant pounding of a high-impact activity such as basketball. And any dramatic weight gain or loss will throw off the foot's performance.

Still, the Proprio shows just how far prosthetics have come. And if such advanced science can increase a person's function, he or she may be less concerned that the device does not look like a natural foot. Recently, one Kessler patient—who had expressed a sensitivity to appearance issues—tried the Proprio. His response? After walking on the unit, he said, “I don't care about cosmetics.”

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Essential to Success

Rehabilitation assistants play a vital part in the physical and emotional recovery of patients

An effective rehabilitation organization depends on individuals with different skills, talents and training coming together as a cohesive unit to deliver the best possible care to patients. One key player on the team—and often an unsung hero—is the rehabilitation assistant (RA). RAs are the equivalent of nursing assistants in acute



Rehabilitation assistants are an integral part of the care team. Some, like Humphrey Jones, use their personal talents to enrich the patient experience.

care, but the title “assistant” doesn’t begin to describe their important role.

To find out more about the work of these essential staff members, *Focus on Rehabilitation* spoke with Mary Ann Brigante, R.N., MSN, CRRN, director of nursing at Kessler Institute for Rehabilitation’s Chester campus, and three RAs from Kessler’s New Jersey campuses: Humphrey Jones of the Spinal Cord Injury Center at West Orange, Lasean Banister of the Stroke Center at Saddle Brook, and Kaydeen Wollary of the Traumatic Brain Injury Center at Chester. Their work highlights the integral role of RAs to the rehabilitation team and serves as a model for the delivery of comprehensive care and treatment.

Mary Ann Brigante, R.N., MSN, CRRN

Focus: What is the overall function of RAs in the rehabilitation setting?

Brigante: RAs assist patients in regaining maximum functional ability and independence, and learning to cope with life-altering changes. Their contribution begins with hands-on care and includes vital emotional support.

Focus: What tasks do they typically undertake?

Brigante: Their work is physically demanding. RAs provide general nursing care like bathing, toileting, dressing, meal set-ups and transferring patients in and out of beds and wheelchairs. They constantly reinforce techniques the patients have learned in rehabilitation sessions, and others outlined in nursing care plans. RAs also assist with ambulation and the donning and doffing of various braces, supports and assistive devices. During meals they monitor dysphagia patients and reinforce therapeutic feeding strategies. They assist in assessing changes in skin, wounds and even mental status. RAs may well be the first to notice a subtle change in the way a person is behaving or responding.

Focus: Given that close, personal interaction, how do RAs help to improve treatment outcomes?

Brigante: Since the goal is to get patients back home, RAs teach, encourage and motivate them to do for themselves. RAs need tremendous customer service skills to deal with the many demands.

Strong bonds often develop between patients and the RA staff. We have RAs who have gone out and bought clothing and personal items for those who don’t have family support. Others come during their off hours to spend time with patients who may have no visitors. All see their role as much more than just a job, and we would never be able to provide such a high level of patient care without them.

Humphrey Jones

Focus: What is your typical day like?

Jones: It begins at 7 o’clock in the morning, and I start preparing my

patients for 9 o’clock therapy. I get them up; change their nightclothes to the clothes they’ll wear for the day; wash their faces and help with grooming; and brush their teeth. They are given breakfast, and then I assist them into the wheelchair to go to the therapy gym. I have to clean the rooms, change the bed linen.

After morning therapy, we feed the patients lunch, then they have afternoon therapy. My shift ends at 3, so I’ll most likely finish by putting my patients back into bed. They can be here for four to six months; in one case, a year. You get to know them well.

Focus: You’re known for bringing your guitar to work and playing after hours. What’s your motivation?

Jones: That’s something I enjoy doing. Sometimes you can use your own experience to imagine what somebody might be going through when they have a crisis in their life. Everybody needs a little lift; it could be a word, a song, some music. I find it rewarding. I play mainly gospel music. The patients love it—they usually give me good comments, and that makes me feel good.

Focus: What kind of person accepts the demanding responsibilities of an RA?

Jones: The job itself is one you can’t take unless you really have a feeling for humanity, because you’re dealing with people every day who’ve had some disappointment, or they’re going through suffering. Some are in a lot of pain. It really makes you want to do what you can, beyond just doing the job. Most of the people I work with are doing it because they enjoy it.

Lasean Banister

Focus: Describe the training RAs go through.

Banister: I’m one of two preceptors [trainers], and we have a very intense orientation program for new RAs. We teach the trainees how to transfer people into and out of the bed. It’s difficult—the stroke patients have left-sided or right-sided weakness, and you need



The responsibilities of RAs can be physically and emotionally demanding, but also are professionally and personally rewarding.

Focus: How do you approach your interactions with patients?

Wollary: I don't really treat them as patients; I treat them as family members. I would want my mom or dad to come to Kessler and not be scared. I want them to feel extra comfortable, as if it were home, and not a rehabilitation center.

When I come in at 3 o'clock, I get a report on my patients. I then go around and greet all of them and start right in by taking them for X-rays or getting them settled back after therapy. If they are tired, I will put them in bed for a rest before dinner. I just want it to feel like home.

to know how to accommodate this. We instruct on how to talk to patients with speech problems, using a training board. You have to take your time and listen. We teach them about safety precautions, too, like wearing gloves. We also discuss the different therapy equipment they need, like how to put on hand braces and leg braces.

Focus: Are you involved in helping a patient's family cope with challenges they face?

Banister: We educate family members on the things the patient might be going through, as well as show them how to assist the person in and out of bed. They usually just like to watch us so they know what to do when they take their loved one home.

Focus: Tell us about a success story you've had.

Banister: When patients come in, they can't do things. Maybe they can't talk. And when they leave, you see them moving or communicating much better. I don't have one success story; I would say that most of my stories are success stories, because when my patients go home, they're better.



Kaydeen Wollary

Focus: How did you come to work in the profession?

Wollary: I started out as a rehabilitation aide in the Physical Therapy Department, and then transferred to the Nursing Department because I'm going to school part-time at Rutgers University to become an R.N. Working at Kessler is really great. I'm in the Traumatic Brain Injury Center, and it's really building my character. I'm a shy person, and you have to be outgoing with patients, and reassure them that everything is going to be okay. When I'm here, I open up—it forces me to have more confidence.

Focus: How will your experience as an RA influence your future career?

Wollary: After I receive my degree, I would love to work in rehabilitation nursing. Working here, you see different things all the time. We had a patient in recently, an anoxic brain injury. He couldn't walk, he couldn't talk, couldn't do anything. And when he walked out of here, I couldn't believe it. He was a completely different person. It was amazing. This place has so many different stories. I find it very rewarding.

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Surprise Package

History shows that bundling payment for post acute care would be fraught with challenges

■ BRUCE M. GANS, M.D.

In the ongoing debate over health care reform, bundling is surfacing again as a payment alternative. This practice involves making a payment to one provider that includes amounts for services supplied by other providers or settings. The amount of the bundle payment is determined on a statistically predicted basis for the services covered. The entity receiving that single payment is responsible for delivering its own services and managing payments for the defined episode of care. The bundle payment recipient gets to keep what is not expended for the patient but must cover any shortfalls.

as bundle owner, would theoretically have an incentive to control the costs of doctors' fees and optimize doctors' hospital visits. Another proposal would consolidate both acute and post acute care payments, letting the acute care hospital decide how to control post acute care costs. The fear in the post acute community is that this would provide an incentive for harsh under-utilization of services.

And we already know a great deal about the true impact of financial incentives and how they drive behavior in hospitals. Even without bundling, we see examples every day in the real world of patients not being given full,

A Familiar Road

Bundling actually is not new, and has been with us under different names, including capitation and managed care. Capitation contracts with insurance companies turned out to be terrible mistakes and financial disasters for many hospitals and health systems in the late 1980s and 1990s. Capitation was simply unfeasible in the real world: Hospitals couldn't manage patient resources as efficiently as needed to sustain their operations.

Managed care provides another close parallel to bundling. Under this system, insurance companies have the ability to direct and force patient flow through contracts and economic incentives. The process created a huge public backlash around choice and access at the peak of managed care. Patients were distraught when they realized they had lost all ability to choose the health care they wanted just when they needed these options the most.

A Thoughtful Approach

Capitation and managed care provide us considerable experience to explain why bundling may sound more fiscally efficient, but in reality is most likely to have a severe negative impact on patient care. We need to monitor health care reform proposals closely, not with a prejudicial eye, but rather with deliberate, honest and thoughtful consideration. We need to make sure that any proposals that invoke bundling are constructed in such a way that they will avoid the problems we experienced under capitation and managed care. We must also be prepared to advocate to protect the interests of both patients and post acute care providers.

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We already know a great deal about the **true impact of financial incentives** and how they **drive behavior in hospitals**.

The policy intent behind bundling is to eliminate micromanagement by the government or other health care payer, yet provide an incentive for spending restraint. The provider (or bundle "owner") would, in theory, have the financial incentive to be a more prudent purchaser and user of all health care services covered by the bundle, including outside services, thus reducing overall health care expenditures.

The Options

We can contemplate many different bundles. For example, the bundle might include physician fees as well as acute hospital costs. The hospital,

correct information about post acute care options, and of payers trying to channel patients into less expensive and less appropriate care settings. Bundling doesn't offer any assurance of improvement in these aspects. The practice is likely to stir up even more competition, with destructive consequences, among post acute care providers and between them and acute care hospitals.

Bundling will likely prove very difficult to do well, and may introduce significant economic risk to the recipient. For example, bundling may burden the bundle owners with developing more expensive decision-making processes and allocating staff to this purpose.

Sexuality and Spinal Cord Injury

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breasts. A study of individuals with complete SCI found that they reported experiencing awareness of vaginal and cervical stimulation, orgasm, analgesia and menstrual discomfort. However, orgasm may cause autonomic dysreflexia (AD), and the person with SCI or her partner may need to monitor blood pressure occasionally during stimulation and intercourse. Women with injuries at T6 and above, as with men, may suffer from AD.

Women with SCI have special considerations with regard to pregnancy. During the prenatal period, they may have problems with constipation, urinary tract infections, decreased vital capacity (unable to take deep breaths), deep venous thrombosis (DVT), pressure ulcers and spasticity. During the perinatal period, there is a higher-than-average risk of premature delivery, AD, DVT and pressure ulcers. In the postnatal period, problems can involve DVT and episiotomy breakdown because of poor sensation combined with prolonged sitting in a wheelchair.

Men's Issues

Most men with SCI with complete upper motor injuries (92 percent) experience reflex erections. However, because their erections are frequently poorly sustained, only 44 percent can have successful intercourse without additional intervention. In men with complete lower motor neuron injury, only 26 percent have reflex erections and 24 percent have successful intercourse. Fortunately, many options exist to treat erectile dysfunction.

One of the best known treatments is the use of oral type 5-cGMP-phosphodiesterase inhibitors, which are reported to be successful 75 percent to 94 percent of the time in men with SCI. Sildenafil, vardenafil and tadalafil are equally effective and well-tolerated. However, they are more effective in those with upper motor injuries (who have reflex erections) than in those with lower motor neuron and cauda equina injuries.

There are concerns with using phosphodiesterase inhibitors in men with SCI T6 and above because they have low baseline blood pressures and the potential for AD. Phosphodiesterase inhibitors can lower blood pressure, especially if they are combined with various medications such as alpha blockers (used for voiding) and nitrates (used to treat AD). Therefore, a rehabilitation specialist with expertise in this subject should be consulted for more details.

Another option is a vacuum device, particularly the hand-held type. Intraurethral prostaglandin instillation is also an option, but the prostaglandin may be absorbed systemically and cause transient hypotensive episodes. Low dose intracavernosal prostaglandin injections are therefore frequently the preferred method to obtain an erection in those with injuries above T6 and in those with lower motor injuries who had poor success with phosphodiesterase inhibitors. Penile implants are discouraged in men with SCI because of the risk of infection and erosion of the implant through the skin.

Men may also suffer infertility following SCI; causes include poor semen quality and/or ejaculatory dysfunction. In the latter case, several methods make sperm retrieval possible, including vibratory stimulation, electroejaculation or aspiration of sperm from the testicle. Use of assisted reproductive technology, in which sperm is directly injected into the partner's egg (intracytoplasmic sperm injection), has significantly

improved the ability of men with SCI to father children.

What About Partners?

Rehabilitation professionals also should consider the concerns of able-bodied partners of individuals with SCI. While this area has not received sufficient attention, one survey revealed that most partners of persons with SCI (84 percent) considered their overall relationship satisfying, and 61 percent appreciated the quality of their sexual relationship. Half of the couples engaged in sex, with or without intercourse, at least once a week. Almost half of able-bodied partners (45 percent) considered their current sex life to be as good as or even better than it was previously. Positive predictors of an active, fulfilling sexual relationship included a varied repertoire of rewarding sexual expressions, including intercourse, and concern about the able-bodied partner's sexual pleasure.

In summary, sexual function is extremely important to men and women with SCI and their partners. Health care providers can help these individuals meet the challenges by taking into consideration changes in body image, medical issues, levels of injury and available options for care.

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VIEWS ON PARENTING AND SCI

In a Kessler study, 13 percent of men with SCI desired having children "now," and 61 percent in the future. Those with children reported that being a parent provided them a sense of purpose and responsibility. In another study, 26 women with SCI who were parents were interviewed; they had 47 children in total. These women felt that their family roles were no different from able-bodied women, and their husbands agreed. These men also reported that they did not have any more parental responsibilities than did husbands of able-bodied women.

Getting a Handle on Headaches

Kessler takes a thorough approach to treating a widespread and vexing disorder

■ JEFFREY L. COLE, M.D.

Too often, the management of acute and chronic headache occurs in relative medical isolation, not taking into account the vast therapeutic options available to patients. Kessler Institute for Rehabilitation has developed a comprehensive, cross-disciplinary program designed to systematically evaluate and manage these afflictions.

Headaches are one of the most common disorders worldwide. In the U.S., at any given time more than 15 percent of adults have had a severe headache or migraine within the previous three months. Patients with brain or spinal cord injury or other neurologic disorders are at an even higher risk.

Several factors have limited the identification and management of acute and chronic headaches. First, they are often misdiagnosed, particularly migraines, which can lead to inappropriate or ineffective treatment. Second, care frequently has overemphasized pharmacological modalities, without consideration of complementary approaches, such as physical or other therapies. Finally, there have been very few direct comparisons of existing treatments; thus, their relative safety and efficacy for a given patient or particular category of headache are largely unknown.

A Logical Methodology

Kessler's comprehensive headache program applies the spectrum of available diagnostic and therapeutic interventions in a stepwise, structured fashion. The first and most important action in the evaluation of a patient is a careful, thorough history and physical examination. This involves staff from the neurology, psychiatry and psychology departments, at a minimum.

Based on the findings of the exam and selected diagnostic tests, the patient's headache can then be placed into one of numerous categories, including cervicogenic headache, neuralgias, or one of the other types listed by the International Headache Society.

Staff members then initiate an appropriate treatment regimen for the patient's specific headache type. The treatment spectrum at Kessler encompasses up to 150 different options, including nerve blocks, various physical and occupational therapies, and pharmacological agents.

Tracking Results

A unique aspect of Kessler's headache management program is the prospective capture of clinical outcomes data from the first patient encounter. With the help of a staff biostatistician, the team developed a thorough intake tool

to record demographic and historical data. Clinical information also is collected during the patient care process. Outcomes data include pain measured on a visual analog scale (VAS), changes in medication use, missed work time, number of headache days per month and the entire Migraine Disability Assessment (MIDAS) questionnaire.

The goal is to create a large dataset for headache types and management therapies. Statistical analysis would then allow direct comparisons of treatment strategies and of choices within a treatment mode or headache type, increasing the evidence base for the management of future patients.

The Next Steps

As the program evolves, the team aims to develop and refine specific management algorithms for patient subgroups on an ongoing basis. For example, persons with brain injury are more likely to have discogenic pain, cervicogenic pain, neuritis or neuralgia. They will likely require diagnostic tests and therapeutic interventions different from those of headache patients without brain injury.

Pediatric and adolescent patients represent a special challenge with regard to headache identification and management, in that their symptoms are often underappreciated and misdiagnosed. The Kessler team is developing outreach efforts for referring physicians and the general community, so that the program's options can be made available to these populations as well.

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