FOCUS ON Parkinson's Disease

A publication from Kessler Institute for Rehabilitation

Rehabilitation

FOCUS ON PARKINSON'S DISEASE is an insidious and degenerative illness that afflicts more than 1 million Americans. Although first used for pain control, deep brain stimulation (DBS) has been heralded as a breakthrough treatment for Parkinson's symptoms that are refractory to standard pharmacotherapy, such as levodopa. Treatment involves sending electrical impulses to the thalamus, subthalamus and/or globus pallidus via direct implantation of electrodes in the brain. Electrical impulses are controlled through programming of a stimulator/battery unit.

The effect of DBS on reducing dyskinesia, tremor and other motor symptoms has been repeatedly demonstrated in the literature. Now, Kessler Institute for Rehabilitation is going one step further and using an innovative approach to address some of the challenges associated with DBS and help patients enjoy more fulfilling lives.

On the Fast Track

The successful application of DBS as a treatment extends beyond the surgical procedure itself. Following implantation, the neurologist must determine optimal programming of the stimulator while concurrently adjusting medications. With traditional approaches, this can be a time-consuming, trial-and-error process that spans several months. It also requires frequent, sometimes daily, clinic visits by patients. While DBS is generally considered efficacious, the standard treatment method can increase the time required for an individual to adapt to the stimulator and complete rehabilitation.

Consequently, Kessler has partnered with physicians from North Jersey Brain and Spine Center and Hackensack University Medical Center to implement a fast-track program that uses intensive monitoring to help patients graduate through rehabilitation more quickly. This inpatient system generally treats individuals post-implantation of the battery stimulator component, although those who require more observation may be admitted prior to implant.

Recipients of DBS are constantly monitored in order to properly adjust stimulator programming and medication, typically through daily evaluations by the movement specialist neurologist. Changes can be implemented in therapy immediately, allowing for prompt feedback to the patient, therapist and doctor.

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PHYSICAL MEDICINE and rehabilitation (PM&R) first developed as a medical specialty and service delivery model in the United States. The field’s multidisciplinary approach later spread globally, though at an uneven pace and penetration. Rehabilitation hospital stays differ considerably worldwide, with most nations reporting substantially longer ones than the U.S. This is probably due to varying financial pressures, cultural mores, availability of PM&R resources and other factors.

In developing countries, community-based rehabilitation, promulgated by the World Health Organization, offers a “training the trainers” approach in which providers teach family and local volunteers to care for patients in home settings. More advanced nations have state-of-the-science acute care systems and are now focused on expanding to provide PM&R programs, typically by seeking cooperative agreements with established providers in the U.S. and elsewhere.

In some places, natural catastrophes have accelerated medical rehabilitation development. For example, western China’s 2008 earthquake directed attention to its inability to care for vast numbers of victims who had disabling injuries. Consequently, the country has started to rapidly expand its PM&R capacity to deliver services in underserved areas.

Where does the U.S. rehabilitation community fit into the international landscape? As frequent first-responders in relief efforts worldwide, we commonly send trained staff—usually humanitarian agency volunteers—to offer services for limited periods. These rehabilitation teams provide invaluable help but, without sustainable infrastructure, it is of finite value. In other instances, patients are transported to the U.S., but again, without ongoing care in the individual’s homeland, benefits from intervention may prove short-lived. Fundraising represents another approach to developing PM&R institutions in the target nation. Efforts in this regard have been made for Haiti.

To build sustainable capacity elsewhere, physician training is essential. Historically, Howard Rusk, M.D., pioneered bringing foreign physicians to this country for specialty training, intending that they return home with their expertise. While not all trainees went back to their native lands, many did and much of the Far East’s current capacity is traceable to his endeavors.

Other nations need physical rehabilitation infrastructure, and today some well-capitalized health care corporations are pursuing international expansion. Through development and partnerships, U.S. companies can enhance global rehabilitation capacity while fulfilling their business missions.

All told, the most responsible approach to expanding the field abroad is by supporting countries in creating facilities and educational opportunities within their borders, making truly sustainable rehabilitation a reality. Organizations such as the International Society of Physical and Rehabilitation Medicine (isprom.org)—which offers peer-reviewed publications and conferences; WHO-sponsored activities; and regional professional societies—all welcome new member countries. Encouraging these developing nations to take advantage of such resources will help their nascent programs endure and thrive.

Our goal should be to develop colleagues and peers who, by contributing to the global knowledge base and participating in the community, will enhance our field worldwide. Clearly, everyone benefits from this model.

Bruce M. Gans, M.D.
Chief Medical Officer
An expanded cardiac program gives LVAD patients a step up in recovery

By Karen Kepler, D.O., Ph.D., and Robert Klecz, M.D.

The notion of a robotic heart may once have seemed like science fiction, but such discoveries are the reality of cardiology today. Although not a replacement for the heart, the left ventricular assist device (LVAD) is a remarkable innovation that mimics the action of the left ventricle and extends lives while increasing the scope of modern cardiothoracic medicine.

For individuals who have compromised ventricular functioning, such as those awaiting heart transplantation, LVAD implantation may improve hemodynamics and coronary perfusion, resulting in reduced mortality. But its uniqueness brings about potential difficulties in medical complications, such as thromboembolic events and infection, and declines in endurance and conditioning, which can impair everyday living. To assist this population in the early stages of healing, Kessler Institute for Rehabilitation is providing the building blocks for improving functioning, quality of life and education through its recently expanded Cardiac Recovery Program.

Meeting Individual Needs

Unlike traditional cardiac rehabilitation, designed to increase cardiac capacity and exercise tolerance, the program is intended for patients who are not ready for the rigors of sustained physical activity or who require a higher level of care. It serves as a bridge between the acute medical setting and the home environment, with a tailored treatment plan designed to meet each person’s rehabilitation goals and needs.

For LVAD recipients, the focus is on building strength, endurance and general conditioning, with the goal of developing the skills necessary to live more independently. In addition, patients learn how to maintain proper operation of the device. The program takes a comprehensive approach, drawing on the expertise of an interdisciplinary team of providers. LVAD patients receive a minimum of three hours daily of physical and occupational therapy, nutritional counseling, and close follow-up with physiatry, internal medicine and cardiology.

While basic education has always been an important part of teaching participants about their diagnosis, Kessler recently revised this particular component to include specific content for optimizing day-to-day living. All patients now receive an education booklet that covers relevant cardiac disease states, such as congestive heart failure, medication use and potential side effects, how to conserve energy during physical activities, and necessary lifestyle changes. Individuals who have LVADs additionally receive material on wound care, managing the operation and maintenance of the equipment, and the importance of psychosocial support. Two LVAD recipients have enrolled in the program thus far and have expressed great enthusiasm toward this education aspect. Patients report a strong desire to receive as much information about this distinctive device as possible, even through informal channels like conversations with providers during daily therapy and nursing appointments.

A Learning Curve

Compared with individuals who have more acute cardiac issues, such as myocardial infarction, the LVAD population often exhibits more severe disease progression and greater debility. Coupled with their declining cardiac functioning, there also may be pertinent psychological issues that affect recovery, including depression and poor adjustment.

But the patients are not the only ones who must adjust to the LVAD; clinicians also are learning how to adapt routine approaches to cardiac care. For instance, traditional methods of monitoring cardiac patients, such as by listening to the heart beat and monitoring blood pressure, are not appropriate for LVAD recipients. Furthermore, the complexity of the device requires a level of competence—and confidence—for ensuring that it is operational and monitoring blood pressure, are not appropriate for LVAD recipients. Furthermore, the complexity of the device requires a level of competence—and confidence—for ensuring that it is operational and teaching patients and family members how to properly care for the LVAD prior to discharge. As patients and providers are acclimating to this lifesaving technology, the cardiac recovery program is helping to turn these challenges into powerful opportunities.

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Drawing on strengths: art therapy’s unique clinical potential

Q&A WITH BARBARA BENEVENTO, M.D., AND MARY MAMRAK, MHA, CTRS

IN THE REHABILITATION setting, art therapy can be an effective component of an overall program, benefiting individuals who have a wide variety of diagnoses. It creates and reinforces skills, builds muscle strength and enhances psychological aspects of rehabilitation, permitting expression of anger and grief, fostering confidence and improving human relationships.

At Kessler Institute for Rehabilitation, patients can engage in creative art projects as part of, or after, therapy sessions. To understand how this treatment can advance clinical outcomes, Focus on Rehabilitation spoke with Kessler’s Barbara Benevento, M.D., director of the Ventilator Program, and Mary Mamrak, MHA, CTRS, senior recreation therapist.

Focus on Rehabilitation: Is art therapy better suited for some patients and not others?

Mary Mamrak, MHA, CTRS: This form of rehabilitation is appropriate for almost all levels of injury treated at Kessler, such as orthopedic trauma, spinal cord injury (SCI), brain injuries and neurological conditions, although it benefits people in different ways. One of the great things about this approach is its adaptability to the needs of each diagnostic group.

In our Art Therapy Program, which is part of the Recreation Therapy Department, we use a range of slings, cuffs and substances. These include pliable clay, colored sand and seasonal items, such as leaves, acorns, grass and flowers. Our art therapist is imaginative and very attuned to the needs of each person, and he has been able to find a way around the limitations of those with whom we work.

For patients, a creative background is not required—art therapy is not about being Rembrandt. It is about having an outlet, building skills, realizing abilities, taking control, expressing feelings, interacting with others and engendering confidence. And art therapy encompasses a range of activities. For example, a person may not gravitate to painting but is enthusiastic about woodworking and utilizing tiles.

Focus: How is it incorporated into the overall rehabilitation process?

Barbara Benevento, M.D.: Sometimes traditional methods are not the only effective interventions. We actively use what happens in art therapy to support the healing process. I engage patients during these creative sessions and open conversations. For instance, I may ask, “Why did you place that blue there? Or why did you choose that particular yellow?” Talking with them about decisions being made in their painting leads to discussion of other topics—concerns or frustrations they may have, their injury or their experience being in the hospital. It is a jumping-off point, and I then may be able to learn about what is happening beneath the surface. Often at the art therapy table, clinicians can have a better sense of how someone is actually feeling. Many individuals will not share this anywhere else.

Focus: In what ways does art therapy build or reinforce skills and increase physical functioning?

Benevento: The intricate motions required in creating art can improve fine and gross motor movements, and working with colors and three-dimensional tasks can enhance visual and spatial skills. Also, many SCI patients need to participate in conditioning activities to build arm strength to improve functioning, but just moving the arms up and down while exercising becomes monotonous. During a creative session, the art therapist uses techniques that incorporate arm movements, and yet the patient is preoccupied...
with the endeavor and not thinking about the exercise. If a person had to lift their arms 12 times for an exercise, he or she would grow tired quickly. But with art therapy it becomes enjoyable. And it is wonderful to actually accomplish something creative while moving.

**Mamrak:** We have people with high-level SCI who have no other way to direct their wheelchair movements except with their lips, and so they need to strengthen the structures in and around their jaw and mouth. With art therapy, these individuals can paint by holding an implement in their teeth; we call it “mouth stick painting.” Another example involves those with limited finger dexterity, who can use a string wrapped around the hand to brush paint on a canvas.

**Focus:** How does this therapy benefit social skills?

**Benevento:** Often two or more patients work on a project together and this fosters camaraderie and the sharing of ideas. The interactions allow for the opportunity to identify with others who also are going through therapy and to talk about how they are dealing with challenges and how they compensate.

**Mamrak:** Along those lines, many social skills need to be restructured following an injury, and arts and hobbies can play an important role in this. Also, in talking with other people around the art table, all patients—regardless of the degree of deficit—learn new perspectives. An individual reluctant to be seen with a walker might start talking with someone else who has been using one for years. And for many who are higher-functioning and will return to the community, an art therapy pursuit will become where they live and other resources near where they live.

**Focus:** What kind of psychological impact can these activities have?

**Mamrak:** Following an injury, there often is a feeling of helplessness, whether it’s involving severe disabilities or more minor setbacks. Many of our higher-functioning patients feel closed off from life and extremely anxious about returning to a sense of normalcy. Art therapy is a place where they can be in control. For those with more severe deficits, it is a way to get them moving and engaged. Sometimes just one positive development is needed and then everything looks a little brighter. For many, I’ve seen art therapy provide that turning point.

As Dr. Benevento mentioned, art therapy tends to help individuals open up. Psychologists participate in some sessions, sitting alongside patients, and this enhances aspects of counseling, helping to draw out feelings and experiences they had been unwilling or unable to verbalize previously.

We have seen examples of this as well. One very depressed patient’s first painting was all in black. Everything about it conveyed sadness. As the sessions progressed, however, he slowly began to add color, and we discussed how this reflected a change in his mood. He went on to express things he had not been able to communicate elsewhere.

A person with brain injury who was depressed and angry, used a rubber mallet, dipping it into paint and slamming it on the paper, splashing colors. This became a stress reliever for him and, again, something we could talk about.

**Focus:** How has this therapy fit into the multidisciplinary framework at Kessler?

**Mamrak:** The physicians and other team members, as well as patients’ families, have all come to appreciate the benefits that art therapy provides. At first, one of our doctors was a little skeptical about art therapy, but he now is a strong supporter. He observed people concentrating at a task for 15 minutes at a time and commented how the increase in attention span would carry over to other activities and generate confidence as well.

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**Mary Mamrak, MHA, CTRS (Certified Therapeutic Recreation Specialist),** Kessler’s senior recreation therapist, has a master’s degree in public administration, health services administration. You can contact her at mmamrak@kessler-rehab.com.
Ensuring the survival of the rehabilitation field in the era of health care reform

By Bruce M. Gans, M.D.

Coping with the Affordable Care Act (ACA) requires staying current on its evolving implementation. Although initially debated and presented as health care service delivery reform, it has emerged primarily as a health insurance and financing revision. There are many points of opportunity and vulnerability for medical rehabilitation in the ACA. Several of the more prominent elements will be reviewed here as activities that should influence the strategic direction of all inpatient rehabilitation hospitals or units (IRH/Us).

One of the early programs that the ACA created is the accountable care organization (ACO). Operationally, it is a consortium of primary care physicians and health care facilities that coordinates care and assumes financial risk for certain patient populations in exchange for opportunities for bonus payments based on shared savings (and shared risk). On March 31, Medicare released specific draft regulations for this type of caregiving model. How the rules will affect IRH/Us or other post-acute providers is not yet clear. At the least, these potentially affected facilities should carefully monitor ACO proposals and developments in their markets. If any developments are identified, IRH/U representatives should contact program organizers, expressing interest in scope of their services or partner with other post-acute care providers to form a virtual CCH.

Protecting Patient Access to Rehabilitation Care
The importance of the ACA in defining the standard for health insurance benefits cannot be overstated. The law calls for establishing health care exchanges (HCEs) at the state level to provide insurance to the “gap group”; i.e., individuals without insurance who do not qualify for traditional Medicaid. While the new legislation mandates that rehabilitation and habilitation be part of the basic benefits for this insurance program, it omits any specific parameters (caps, therapy types, frequency). And, although the ACA prohibits insurers from establishing lifetime limits or denying preexisting condition coverage, it offers no such protection for specific services like rehabilitation.

Conceivably, an individual could buy a policy with unlimited overall coverage, but unreasonable rehabilitation care restrictions. We must strongly advocate for revisions that incorporate robust benefits. Of major note, because the HCE benefit plans may become the standard that Medicaid and commercial insurance providers emulate, ensuring that its definition is fair and supportive of rehabilitation is a top advocacy priority.

Recently, the National Association of Insurance Commissioners convened a working group to develop a consumer-level description of benefits offered by HCEs. At the last moment, medical specialty representatives discovered that this group was planning to adopt very inadequate language to describe the rehabilitation benefit. Only through intense, last-minute advocacy was the field able to intervene, obtaining more favorable text in the report.

Also, the U.S. Department of Health & Human Services engaged the Institute of Medicine to make recommendations on the HCE benefit plan as well. Specialty advocates again interceded—providing written testimony about coverage for medical rehabilitation—in another effort to promote access to this new insurance program.

Through legislative monitoring and public policy activism, the field can advocate for robust medical rehabilitation coverage. Assuming that health care reform activities continue to move forward, these new programs will affect millions of individuals.

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A boost for the benefits of deep brain stimulation
(continued from page 1)

Thus, the fast-track program not only eases the clinical adjustment period, but it also allows inpatient rehabilitation to begin quickly as an integrated, core component of the treatment regimen. There is a collaborative approach, drawing on expertise from specialists in neurology, psychiatry, speech and occupational therapies, psychology, neuropsychology and psychiatry, who assess global changes in symptoms and treatment response. For instance, postoperative physical therapy helps individuals address difficulties with range of motion, gait and stability. Speech therapy assists with communication and swallowing dysfunctions. Occupational therapy focuses on improving activities of daily living, including maintaining hygiene, feeding and writing. And neuropsychologists use test batteries to examine changes in cognitive processing, such as attention, memory and verbal fluency, which may alter the course of treatment.

Because patients are on-site and have continual access to care, there is maximal contact with these specialists. With an outpatient approach, individuals could potentially become burdened by the scheduling of multidisciplinary clinical visits across different days, but this system makes rehabilitation efficient yet still comprehensive.

Inside the Numbers
Kessler’s emphasis on providing evidence-based care highlights the importance of gathering empirical data on individuals in the fast-track program. As such, participating patients complete rating scales developed to evaluate the progression of motor impairment and physical disability associated with Parkinson’s. The Unified Parkinson’s Disease Rating Scale (UPDRS) is one of the most commonly used assessments of Parkinson’s-related disability and impairment and measures a range of symptom categories, including activities of daily living, behavior and cognition, motor functioning, and dyskinesia. The Functional Independence Measure (FIM) is another method used to rate rehabilitation outcomes and progress, like self-care, mobility and communication abilities.

As a whole, individuals in the program have shown marked improvements on these tools, including a reduction in symptoms and progressions in everyday functioning, often in as little time as less than one week postoperative DBS programming. One patient in particular—a 68-year-old man who had a six-year history of Parkinson’s disease—exhibited pronounced advancement on the motor component of both the UPDRS (88 percent improvement) and the FIM (64 percent improvement) scores, along with a 50 percent reduction in medication, within only five stimulator adjustments. These outcomes were observed after nine days of inpatient rehabilitation—a vast enhancement over the weeks or months it otherwise would have taken to determine optimal programming and pharmacotherapy in the outpatient neurological setting.

Individualized Care
Following discharge from the program, patients are regularly assessed by experts in neurosurgery, movement disorder neurology and psychiatry, depending on their specific needs. Ongoing home-based or outpatient rehabilitation allows clinicians to further address functional deficits and refine the treatment plan as needed. This patient-tailored approach, combined with the efficiency of its inpatient protocol, provides an invaluable opportunity for individuals who have been battling the debilitating effects of Parkinson’s to receive aggressive therapy, rehabilitation and medical attention on a daily basis.

LOOKING BEYOND THE BODY
Although clinical indicators like motor and functional skills are usually the primary component of emphasis in outcome monitoring, Kessler Institute for Rehabilitation’s fast-track program places equal weight on assessing psychological and emotional factors. It is not uncommon for DBS patients to exhibit postoperative psychiatric symptoms and difficulties, even when physical functioning has improved or been restored. Such experiences may include:

• A greater need for social support, in terms of providing physical care as well as for reducing distress and enhancing coping
• Depressed mood or anxiety, often related to the physiological target of stimulation, especially the limbic system in the subthalamic region
• A decline in self-esteem, particularly when occupational or social losses have occurred

As a result, psychologists are routinely involved as members of the rehabilitation team in Kessler’s DBS program. Providers gather patient satisfaction data, which draw attention to potential challenges that might make completion of the protocol more difficult. Assessments of health-related quality of life are also included and help identify psychosocial areas in which a patient may benefit from focused attention. This approach gives the medical team a more comprehensive look at how DBS affects not just the disease, but, more importantly, how it affects the individual.

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AT ITS MOST BASIC level, massage addresses the universal human need for touch, for connection. In clinical settings, where many procedures and treatments are painful or stressful, therapeutic massage (TM) serves as a reminder of more positive types of contact and complements a holistic approach to rehabilitation.

The benefits of TM relate to the “gate control” theory of pain. Thin nerve fibers originating in the skin’s receptors for touch, pressure and vibration—can hinder transmission of these signals. The greater the stimulation of the thick fibers versus the thin fibers, the less pain is felt. This phenomenon explains why people tend to rub an area that aches.

During rehabilitation, tight muscles or those in spasm compress blood vessels and nerves supplying nearby tissues, possibly causing ischemia and associated pain. Stretching such muscles along with undergoing TM improves the local circulation. TM also reduces swelling and formation of excessive scar tissue while enhancing flexibility and range of motion. Given these potential benefits, all patients at Kessler Institute for Rehabilitation are eligible to receive some form of TM.

Methods of TM include Swedish massage, or effleurage, consisting of long, gliding strokes along the skin. The resulting relaxation of surface muscles aids in the preparation for physical or occupational therapy. Motions are made toward the heart (centripetally) to encourage blood and lymph circulation. Myofascial release, a more intensive method, eases restrictions in muscles and connective tissues. Neuromuscular massage is used to relieve specific pain points, and chair massage consists of short sessions concentrating on the upper half of the body.

At Kessler, the individual situation dictates the frequency and intensity of TM. As with other aspects of rehabilitation, the team—including the attending physiatrist, physical therapist and occupational therapist—confers frequently with the primary care physician about the best course of action.

Massage therapists at Kessler differ in important ways from those in free-standing massage centers. In addition to being trained in methods for relaxation and stress relief, Kessler staff must remain current in procedures for specific conditions, ranging from knee replacements to stroke to spinal cord injury.

The potent power of massage for pain management, flexibility and holistic care

BY JEFFREY L. COLE, M.D., AND ROCHELLE SCHUSTERMAN, NCTMB

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