

Rehabilitation

A publication from Kessler Institute for Rehabilitation



Dangers following critical illness: myopathy and polyneuropathy

♦ Samuel Grissom, M.D.

Patients who have been in the ICU for longer than a few days frequently experience generalized weakness. Acute care hospitals recognize the condition, but sometimes miss the cause—critical illness polyneuropathy (CIP) or critical illness myopathy (CIM). Because these problems slip under the radar screen for many physicians, patients with CIP and CIM may not be properly diagnosed or receive the intense rehabilitation care they need.

With CIP and CIM, patients usually recover in weeks to months after discharge from the hospital, but some can have persistent impairments for years or even for life. Better efforts by ICU physicians and other doctors to identify patients

with CIP and CIM may help ensure that these individuals receive comprehensive inpatient rehabilitation.

One reason for the underdiagnosis of CIP and CIM is that the weakness experienced by ICU patients was at one time assumed to be a result of debility from being bedridden. However, in the early 1980s, studies showed that the abnormalities were often a result of actual degeneration of the nerves and/or muscles. Discussions to explain these symptoms soon appeared in prominent medical journals, and a number of additional terms were used to describe the syndrome: neuropathy of critical illness, ICU neuropathy, acute quadriplegic myopathy and acute necrotizing myopathy.

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Focus on

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**Life, death and rehabilitation**• *Bruce M. Gans, M.D.***T**

his year's tragic "right-to-die" saga of Terri Schiavo threw into sharp relief the ethical dilemmas we face every day.

While Ms. Schiavo's case was a high-profile example, it was, sadly, not an isolated one. The issues to which it gives visibility—chronic disability and family conflict, self-directed care and the withdrawal of life support, brain injury rehabilitation and futile medical treatment—are familiar to us all.

Although we typically are not called upon to withdraw nutrition or ventilator support, we routinely face other serious ethical dilemmas. We often have to help patients define their wishes regarding resuscitation in case they are unable to communicate, and we are repeatedly challenged to determine whether further inpatient rehabilitation will produce enough benefit to warrant longer hospital care.

The medical marketplace is also rife with conflicts. How often do we run into mandated caps on insurance coverage, pitting our ethical duties as providers against patients' needs for continued therapy?

But perhaps the toughest dilemmas are those that arise between us and our patients. I vividly recall times when I have had to acquiesce in patients' decisions even when I knew their choice would put them in an unsafe environment, given their disability. Time and again throughout my career, I have been challenged to accept my own boundaries as a physician—to give patients the best counsel I could, but then step back and support their autonomous decisions, even when I thought those were wrong.

And heartbreaking dilemmas occur when seriously disabled patients contemplate, as some do, taking their own lives. Like many physicians, I have been approached by patients who ask for help in achieving that end, and I've been blindsided by the suicide of a patient who saw his handicap as too great, when I saw him as having an excellent prognosis. Remaining optimistic—and honest—with patients is perhaps the most constant challenge of them all.

Given these realities, what is our role? Our job is to provide hope, to help patients look past their loss and realize they can enjoy a high quality of life with a disability, even if the impairment is irremediable.

At the same time, we need tools to help resolve seemingly intractable conflicts. Keeping an open culture of communication will foster team problem-solving. Formal resolution mechanisms should play a vital role. Every facility should have an active ethics committee. And having access to a professional ethicist—either on staff or as a consult—can be invaluable in breaking through to common ground.

As brain injury rehabilitation advances, devastating cases like Terri Schiavo's may become fewer. In the face of catastrophic injury, we can remain cautiously optimistic about our ability to help patients achieve their true potential. At the same time, we must remember that death is a natural part of the life cycle. Along with improving our patients' functional status, sometimes helping them become comfortable with "a good death" is an essential part of our role.

Physician extenders in rehabilitation: a win-win-win

♦ Robert Krotenberg, M.D.

Physician extenders play an invaluable role in medical rehabilitation facilities, benefiting patients, physicians and the facilities themselves. Because of physician assistants (PAs) and nurse-practitioners (NPs), patients receive more direct care, doctors are able to spend more time treating patients, and the facilities can provide quality care that is also highly cost-effective. Physician extenders also provide backup for absent physicians and help hospitals accommodate a larger patient population.

At Kessler Institute for Rehabilitation, for example, three NPs are employed. One was hired recently as a full-time staffer to provide a variety of services in the medical inpatient department. She performs physical examinations, takes patient histories, writes medication orders and makes changes in treatment and medication regimens. Physician extenders at Kessler do not provide rehabilitation care to patients or fill in for physiatrists. But a dedicated and highly qualified NP can help optimize patient rehabilitation by preventing or treating the multitude of medical conditions that could hinder therapy, such as skin breakdown in spinal cord injury patients. Another important role of the NP is to help prevent recurrence of the original injury or illness—for instance, helping in the treatment of a stroke patient with coagulation therapy, antihypertensives, statins or a combination of these.

Two additional NPs have provided support for the Kessler outpatient urology department for two years. Most clients are spinal cord injury patients with complex urological needs, and the NPs render care based on guidelines for bladder

management in persons with spinal cord injury, assist in cystoscopic procedures and do urodynamic studies to measure neurogenic bladder capacity, flow and contractability, using electromyography. Medical management of these patients is crucial for preventing emergencies, such as autonomic dysreflexia.

The major difference between PAs and NPs is their relationship to physicians. PAs practice medicine under the direct supervision of a physician, while NPs work with physicians in a collaborative model. This is because NPs practice nursing under the state nursing regulation rather than the state medical practice act, which applies to PAs. In addition, PAs are educated in a broad spectrum of medical and surgical care, while NPs study a specialty. NPs also differ in that they are registered nurses with an advanced education at the master's level; PAs require a minimum of two years of college credit before entering a PA program, which is about two years in duration. Both professionals must pass certification exams to be licensed by the state. Kessler has chosen to employ NPs to help meet the demand for high-level nursing skills in the rehabilitation setting.

Although these professionals represent a cost-effective way to provide quality care, not all insurance companies reimburse for NPs and PAs. For those patients at Kessler without coverage for physician extender care, therefore, only physicians provide services. Medicare and



Highly trained nurse-practitioners provide a range of medical services in collaboration with physicians and can be good for patient care and cost-effective for healthcare facilities.

Medicaid do recognize physician extenders, however, and currently pay NPs and PAs 80 percent of what a physician would earn for the same services. If more insurance companies follow the lead of government, physician extenders will play an even greater role in the future, helping to make doctors more efficient and providing cost-effective medical care to rehabilitation patients.

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Putting an end to ‘24-hour bouncebacks’

A study of medical errors shows that the handoff from acute care to rehabilitation is sometimes imperfect

In its landmark 1999 report *To Err is Human*, the Institute of Medicine shone a harsh light on medical errors and the potential threat they pose to patient safety. Many studies have since tried to quantify rates of different types of errors. But very little research has focused on errors in rehabilitation.

Why? “You hear a lot about more visible errors, such as wrong-site surgeries,” says Sunny R. Kim, M.D., a senior resident in psychiatry at the University of Medicine and Dentistry of New Jersey–New Jersey Medical School in Newark, N.J., who received training at Kessler Institute for Rehabilitation. “Errors in rehabilitation tend to be more subtle and are related to the systems and communication used when patients transfer from acute care.”

Working under the direction of Bruce Gans, M.D., Kessler’s chief medical officer, Dr. Kim has added to the sparse literature on errors in rehabilitation with a study of “24-hour bouncebacks”—those patients who must return to acute care hospitals within 24 hours of being admitted to rehab facilities. Earlier this year, Dr. Kim’s research won the 2005 American Psychiatric Education Council Award on Errors in Medicine. He recently spoke with *Focus on Rehabilitation* about the study and the lessons it offers.

FOCUS: Why do you consider ‘24-hour bouncebacks’ to be errors?

KIM: These patients are being transferred from acute care to a rehabilitation facility when they aren’t yet medically or socially stable enough to participate in rehabilitation. That constitutes a major error.

The trend we’re seeing is for patients to be transferred out of acute care “sicker and quicker,” as the saying goes, so the potential for these errors may well be on the rise.

FOCUS: How prevalent is the problem of 24-hour bouncebacks?

KIM: We did a retrospective chart review of 6,712 discharges to Kessler over a 12-month period. We found that 123 of those patients were bounced back to acute care within 24 hours, representing 1.8 percent of all admissions.

That’s just a small fraction of rehab admissions, but the effect of those bouncebacks is substantial when you consider the impact on patients’ lives. A bounceback

can have significant medical and psychological ramifications for the individual patient, as well as financial costs for both patients and the health care system.

FOCUS: Did your study look at why bouncebacks occur?

KIM: Yes. We inquired about the reasons why patients had to return to acute care and found that the major ones were cardiac and pulmonary emergencies. Others included altered mental status, GI-related problems, suspected deep-vein thrombosis or pulmonary embolism, anemia, and bleeding disorders.

FOCUS: Aren’t there systems in place already to ensure that patients are transferred appropriately?

KIM: There are. Rehabilitation nurses now go to acute care hospitals to review patients’ charts to see if they should be transferred. And the psychiatry consultation is another system we use, in which psychiatrists



Studying errors can pave the way for enhancements in patient care. Bruce M. Gans, M.D., and study author Sunny R. Kim, M.D., agree.

consult with transferring patients. But both of these types of review depend on the accuracy of the patient chart—and inaccurate charting is a key cause of bouncebacks. Vital information from the acute care setting—on patients’ comorbidities, current medications or the results of relevant diagnostic tests—often goes missing during the transfer process.

FOCUS: Did your research indicate any solutions?

KIM: Our findings suggest that we certainly need to improve our early-alert and intervention systems. We also need much better ways to communicate patient records to make sure we get complete information on which to base transfer decisions. Some acute care hospitals now use electronic medical record systems, which help provide more complete discharge information.

We should also consider requir-



ing new types of information before patients are transferred to rehabilitation. Patients with cardiac problems, for instance, should have a cardiac consult before their transfer, while patients who are at risk for deep-vein thrombosis should have documented DVT prophylaxis.

We also found that a significant number of patients were bounced back because of anemia. These bouncebacks could be prevented by establishing hemoglobin level admission criteria at rehabilitation facilities. On the flip side, those of us in rehabilitation may want to think about providing blood products in our own facilities instead of transferring patients out for transfusion.

The data suggest that both acute care and rehabilitation facilities should consider adopting these types of new standards to reduce the number of transfer errors. Of course, setting standards won't have any impact unless we all adhere to them—and given the amount of competition for patients, that might be a problem. If different rehabilitation facilities have different admitting criteria, we won't be able to improve overall patient safety.

FOCUS: Do you plan on continuing your research after residency?

KIM: Absolutely. This summer, I'm starting a practice in Cedar Rapids, Iowa, which will serve an inpatient rehabilitation unit that is part of an acute care hospital. So I'll be able to look at systems changes to improve patient transfers from both sides.

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Psychological services help ease the trauma of spinal cord injury

♦ *Loran C. Vocaturo, Ed.D.*

The psychosocial implications of spinal cord injuries are many, and may interfere with a patient's quality of life or participation in rehabilitation. The rehabilitation psychologist strives to prevent or ameliorate psychological symptoms, help spinal cord-injured patients develop a sense of control over the new rules that govern their bodies and learn to integrate those rules into everyday life.

Years ago, the primary concern of spinal cord injury patients was survival. Today, patients can achieve long-term psychosocial adjustment to disability and an acceptable quality of life in the community. However, these individuals also face a wider range of medical and psychological needs. An interdisciplinary medical rehabilitation team is therefore needed to identify and resolve the complex medical and psychological issues of spinal cord injury—issues that change over time.

Comprehensive assessment, various psychotherapy techniques and patient education are the main modes of psychological treatment. Through the use of neuropsychological tests, the psychologist determines the nature and extent of any cognitive impairment, which affects as many as 50 percent of spinal cord injury patients.

Counseling and education allow patients to work through the emotional and physical implications of their injury. They also help relatives adjust to new roles and family dynamics. Treatment will vary in type, frequency and duration according to individual and family needs, and may include the use of antidepressant and anxiolytic medications.

Group therapy is another vital component of a comprehensive pro-

gram. It provides peer interaction and support, both important to spinal cord injury patients. Because negotiating the real-world environment is the first step toward community reintegration, psychologists recommend that patients spend time outside the hospital prior to discharge. Home visits help identify new issues and ease the patient and family into their new situation. Patients also spend time in Kessler's independent living apartment, which helps to identify physical and psychosocial issues in a safe environment.

Psychologists with expertise in spinal cord injury understand the many physical and psychological complexities involved in adjusting to disability. Over the long term, patients must adapt not only to the physical limitations imposed by the injury, but also to secondary medical conditions such as pressure sores, bowel and bladder problems, spasticity, chronic pain and sexual dysfunction. These conditions can cause more distress than paralysis, contributing to psychological symptoms years after the injury. Psychological services may therefore be needed long after discharge.

Psychology services are designed to help spinal cord injury patients adapt to their disability as they seek balance in their lives. This new balance will include securing a personal identity, finding a place for their disability and developing and maintaining a purpose in life. When the disability is no longer the patient's dominant concern, adjustment and adaptation have been achieved.

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GAO's new recommendations: too little, too late?

♦ Bruce M. Gans, M.D.

This spring brought the next puzzle piece into play in the continuing saga of how Medicare defines rehabilitation hospitals and units using the “75 percent rule.” In April, the Government Accountability Office (GAO, formerly the General Accounting Office) issued the report requested by Congress on the skewed 75 percent rule that took effect last July.

The GAO report reflected several of the criticisms we have leveled at the rule since it was issued by the Centers for Medicare and Medicaid Services (CMS) last year.

Fortunately, the GAO agreed, for instance, that the rule does not accurately reflect the needs of patients in inpatient rehabilitation.

Further, the agency accepted the idea that patient function—not just condition—should determine who needs intensive rehabilitation, and that research into the effectiveness of different rehabilitation settings needs to be done.

Unfortunately, the report did not actually answer the questions Congress posed: Is the current 75 percent rule clinically appropriate, and what additional conditions should be added to it? In fact, the report specifically concluded that no conditions should be added and that further restrictions on existing groups should be developed. It was not the enlightened review the rehabilitation field was hoping for.

A rule run riot

In the meantime, the CMS's rule has been wreaking havoc, even before the progressively steeper percentages mandated by the rule start to mount.

Occupancy rates in some rehabilitation hospitals have already

plummeted 40 percent. Several sites have permanently closed beds, while at least one free-standing facility has shut its doors for good. If we don't succeed in getting this rule scrapped or at least held to 50 percent, I predict the U.S. will lose as many as 40 percent of its inpatient rehabilitation beds by the time the full 75 percent rule takes effect.

If you think I'm exaggerating, consider this sobering GAO statistic: Only 6 percent of inpatient rehabilitation facilities in fiscal year 2003 were able to meet the CMS' 75 percent threshold. We are on the

As the era of Baby Boomer Medicare

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brink of a drastic constriction of the field precisely when the need for our skills and service is about to explode due to the Baby Boomer generation. In the not too distant future, even patients who qualify under the CMS's rule may not be able to find the treatment they need.

Here is another disturbing trend: Some facilities, in a desperate attempt to find patients who meet the CMS's defective rule, are treating patients well beyond their expertise. Facilities that have never cared for burn patients, for example, are now accepting them, while institutions that lack a spinal cord injury program are vying to admit those patients. These are the types of temptations all of us will face as the 75 percent rule increasingly distorts the rehabilitation marketplace.

What can we do? First, we need to endorse and build on the few GAO recommendations that we agree with, and actively propose to conduct the research that will set standards and effectiveness measures for different types of rehabilitation.

More facilities may close

At the same time, since we disagree that other settings—such as skilled nursing facilities—are equivalent substitutes for inpatient rehabilitation, we need to ensure that strenuous standards and regulations are applied to those settings and that they are monitored to demonstrate appropriate care.

Even more important, we have to take a long, hard look at the distortions being promoted in the rehabilitation market. Instead of opting to deliver clinically unwise care for the sake of compliance, some institutions will face the onerous decision of shutting down, enabling surviving facilities to serve effectively the patients who both need care and are compliant with the rule.

That sounds, I know, like a desperate tack, but it may be called for, given the crisis our field is facing.

As the era of Baby Boomer Medicare draws ever closer, it is inconceivable that a rule that denies needed patient care will be allowed to stand. The GAO report may be the chisel that can expand the cracks in the 75 percent rule's flawed facade. Until the rule crumbles away, we need to work together to safeguard the best of our skills and services.

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The roles of myopathy and polyneuropathy after critical illness

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The pathogenesis of CIP and CIM is still poorly understood, and further research is needed to uncover the causes of these conditions and ways to prevent or treat them. Researchers now believe that CIP and CIM comprise a spectrum of symptoms. This is supported by the fact that patients often have both conditions.

The term critical illness polyneuropathy and myopathy (CIPNM) reflects the fact that nerve and muscle involvement often coexist in patients. The CIP component is an acute axonal sensory-motor polyneuropathy, while CIM is a primary myopathy. Recent studies using histologic evaluation of muscle biopsies in patients reveal that there are frequently signs of both primary (necrotic fibers) and secondary (muscle denervation) myopathy, indicating that both CIP and CIM are present.

Signs of these problems

Symptoms of CIPNM are mild to severe weakness; muscular atrophy, particularly in the lower limbs; impaired distal sensation; limited endurance and delayed weaning from the respirator. Both CIP and CIM are strongly associated with mechanical ventilation use, multiple organ failure and sepsis, although none of these factors are necessary for a diagnosis. One proposed mechanism is that in septic patients, the systemic inflammatory response syndrome that causes multiple organ failure also leads to CIP and CIM.

The prevalence of these conditions is also unclear. Some studies indicate that up to 57 percent of patients in the ICU for seven days or more—and 68 percent to 100 percent of patients with sepsis or

systemic inflammatory response syndrome—will have CIP or CIM. Other studies indicate a lower incidence, a discrepancy that may be due to the use of different diagnostic criteria. Most researchers report that electromyography and nerve conduction studies are needed to make the diagnosis, but there is



If myopathy or polyneuropathy complicates recovery from critical illness, rehabilitation can help patients get back on their feet.

no clear evidence that an invasive muscle biopsy is necessary, except to further classify the condition.

Treatment remains elusive

There is no direct treatment for CIP and CIM; for the most part, management consists of resolving the conditions that resulted in the patient being transferred to the ICU. Hyperglycemia and sepsis are associated with the underlying conditions, which should be aggressively managed and controlled in the

acute care hospital. An intensive insulin protocol is encouraged, and early identification and treatment of infection in high-risk patients can help to avoid sepsis. Other factors that may improve or prevent CIP and CIM include supportive care that limits end-organ dysfunction, such as the use of low-tidal-volume ventilation for patients with adult respiratory distress syndrome. Ventilator-associated pneumonia often can be avoided with the use of semirecumbent positioning and protocols that provide daily interruptions of sedative infusions.

More judicious employment of neuromuscular blocking and corticosteroid drugs can also help. Neuromuscular blocking drugs, used in surgery, can build up in the system in the event of liver or kidney failure, causing muscle weakness. This buildup can contribute to CIP and CIM.

The path to better management of CIP and CIM lies in early diagnosis and intervention, and diagnostic testing should be considered for all patients with unexplained weakness after recovery from or during a critical illness. Although the prognosis is favorable once the patient leaves the acute care hospital, these conditions result in substantial morbidity, mortality and costs, and could likely be improved with earlier diagnosis and more timely intervention. To achieve this goal, however, more awareness on the part of the medical establishment is needed, as well as further research into the causes of and treatments for CIP and CIM.

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Stroke patients' rehab needs continue long after discharge

♦ *Yekyung Kong, M.D.*

For individuals recovering from stroke, inpatient therapy is one very important step in a long journey. Typically occurring in stages, recovery from a stroke is most evident in the first month and lessens slightly by six months. Beyond one year, recovery slows significantly, so it's crucial to make the best use of that first year.

Stroke patients usually spend less than a week in an acute care hospital, then from a week to a month in an acute rehabilitation facility. Those not ready to go home at that point may also spend time in a skilled nursing facility. Even after that stay, however, much of the critical first year remains.

Therefore, most patients who are recovering from stroke require an outpatient program to reinforce gains already made and to further develop the compensatory skills needed to return home and to work and leisure activities. Close medical management during this stage also helps to prevent further strokes and allows doctors to monitor patients for myriad possible stroke-related complications.

In outpatient therapy programs, patients continue to receive physical therapy, occupational therapy and/or speech therapy in order to maximize functional independence.

They are also helped at this stage to develop compensatory strategies for the workplace and home. In fact, some issues, such as driving, can best be addressed months after the stroke, in the outpatient phase. And psychological problems including depression are likely to appear later rather than earlier.

In the outpatient setting, the medical rehabilitation team is able to introduce a variety of tools to manage problems. For example, acupuncture or botulinum toxin treatments may benefit individuals with spasticity or pain. Braces can improve a patient's gait and level of safety and, for appropriate individuals, body weight-supported treadmill training may also be beneficial. Electrostimulation can help improve motor recovery and help people overcome swallowing problems.

Besides reinforcing rehabilitation gains made in the inpatient setting, outpatient therapy programs can prevent or identify further medical complications. Contractures, pressure sores, compromised mobility and problems with communication and swallowing are among the challenges stroke survivors often face.

Outpatient programs for stroke survivors allow physicians to manage medication regimens and use other methods to prevent secondary



Outpatient rehabilitation programs offer benefits to patients following a stroke.

strokes. Commonly used drugs include aspirin, coumadin, anti-hypertensives, cholesterol-lowering agents, antidepressants and various pain medications. Psychological counseling is also provided to help patients and families cope with lifestyle changes and personal challenges.

Although many stroke patients will have long-term residual disability, a comprehensive outpatient stroke program helps to reinforce functional gains and allows individuals to build on the progress they have made in the inpatient phase.

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