

Rehabilitation

FALL 2013

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Rehabilitation for spinal cord tethering facilitates functioning in spina bifida patients

BY JEREMIAH D. NIEVES, M.D.

THE SURGICAL CLOSURE OF poorly fused vertebrae is vital to preventing the prolonged exposure of spinal nerves and tissues that characterize the most severe forms of spina bifida. Without the procedure, patients would be at high risk for life-threatening infection.

Individuals with spina bifida are already vulnerable to developing numerous deficits in neurological, musculoskeletal, bowel and bladder functioning. Spinal cord tethering, a condition that may be associated with surgical closure, could introduce additional impairments or exacerbate existing ones—further interrupting functioning and quality of life. At Kessler Institute for Rehabilitation, the Spina Bifida Services program is helping patients turn this potentially debilitating circumstance into another opportunity for recovery.

A Stubborn Situation

The normal positioning of the spinal cord within the vertebral column is free-floating, loose and flexible. A secondary effect of surgical closure for spina bifida sometimes arises when scar tissue forms and causes the cord to become stuck or “tethered” to the column wall. Although tethering is largely associated with surgery in spina bifida, it also can be diagnosed as a congenital condition and may be related to certain types of spinal trauma in children as the spinal cord grows.

The resulting constellation of symptoms can include distal weakness (often asymmetrical), pain, sensory abnormalities (e.g., heightened response to temperature), bladder or bowel incontinence, sexual dysfunction and ambulatory deficits—collectively known as

TETHERED SPINAL CORD



tethered cord syndrome. Diagnosis is usually through a combination of radiologic abnormalities and physical examination. But individual presentations include a wide spectrum of severity and functionality. Some patients may experience gait issues but no incontinence; others might manifest severe motor weakness or sensory disturbances, while sphincter capability is relatively preserved.

The clinical course and developmental trajectory also vary and to a large extent depend on whether spinal cord tension reaches the threshold at which it causes symptoms to become evident. *(continued on page 7)*

FOCUS ON
Rehabilitation

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In health care policy-making it's the money, not the principle



IN A DECISION-MAKING process, there are three themes to evaluate: technical, political/social and economic. For example, when a group of people is deciding where to go for dinner, there must be concurrence about the type of food (technical), the cost (economic), and who is willing to participate (social/political). A convergence of all three factors is necessary for successful decisions to be made in business and public policy.

Here is an example from the health care industry: Developing a treatment for a rare disease tends not to occur unless a strong technical capability to do so is matched with a social will to allocate funds for a problem that affects only a small number of people. Even in today's world of expanding insurance availability, economic concerns tend to loom large in any decision.

No matter how compelling the technical or social arguments for a given public initiative, a program cannot succeed unless sufficient money is available. Currently, post-acute care is being scrutinized from this fiscal perspective. The quality of care provided by different rehabilitation settings is strikingly devoid of consideration at the policy level. Decision-makers appear to be looking for short-term monetary gains without fully comprehending the long-term health and function of patients, and the economic or social ramifications.

There has also been a pressing concern to fix the Medicare Physician Fee Schedule because of a problem with the Sustainable Growth Rate (SGR) formula. Historically, Congress has passed only incremental deferrals on fixing the remittance method to avoid payment reduction, and the situation continues to grow in magnitude. At present, there are serious conversations in Congress to look at a permanent fix to the SGR problem, but inexplicably, the "pay for" is being focused on the community of inpatient rehabilitation hospitals and units.

With the dollar appearing to trump social and technical factors, our field has to advocate vigorously for itself. The reality that growth in federal health care spending for rehabilitation hospitals is essentially flat over the past nine years, while almost all other segments have doubled, needs to be understood and used as a rational defense against further unwarranted budget cuts. We all must work on saving money by doing the job right the first time.

With the dollar appearing to trump social and technical factors, our field has to advocate vigorously for itself.

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

Functional MRI: Bridging the science and practice of rehabilitation medicine

> GLENN WYLIE, D.PHIL.

IN NEUROREHABILITATION, magnetic resonance imaging (MRI) uses pulse radio waves to create a static picture of the brain that can be immensely useful in facilitating diagnosis and assessing treatment response. But its functional variant, known as fMRI, goes the additional mile by revealing not just anatomy but also activity, giving scientists a window into the brain—and turning researchers into mind readers.

Images of the Mind

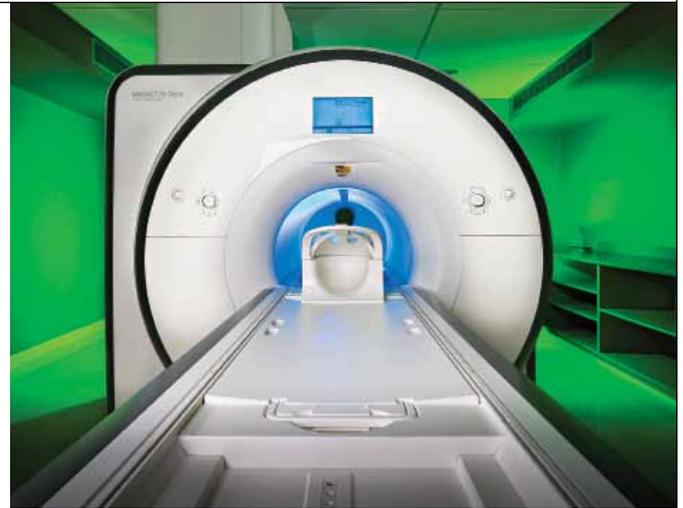
The distinction between an MRI and an fMRI can be likened to looking at a black-and-white picture versus one in color. And for patients with neurological deficits, the telltale differences in brain activity convey an important story about the functional status of the mind under various conditions—such as following an injury or before, during or after neurological treatment. Compared with traditional imaging techniques, which are not able to indicate neuronal activity, fMRI helps researchers more precisely characterize areas of brain damage after injury or diagnosis of a neurodegenerative illness. It also can help clarify the value and outcome of a given intervention focused on recovery of a specific cognitive ability.

For example, processing speed is a known deficit associated with multiple sclerosis that can impinge on other cognitive functions, such as memory, as well as quality of life. But the neurological underpinnings responsible for decreased processing speed are unclear. Identification of these areas through fMRI helps elucidate brain-behavior connections and may influence the development of interventions. In stroke patients, fMRI can be used to help assess the effectiveness of aphasia therapy. Recently, fMRI has shed light on the seriousness of even mild-severity traumatic brain injury (TBI) in terms of subsequent post-injury memory and executive function deficits.

A Clinical Connection

Because of complexities in image acquisition and data analysis, and the fact that researchers are more likely to have the time, experience and expertise to understand and overcome these obstacles, fMRI use in rehabilitation settings is currently restricted primarily to research rather than clinical application.

In May 2013, the Kessler Foundation Research Center opened the Neuroimaging Center, which is currently the only free-standing research facility in the nation with an imaging center entirely committed to inquiry involving clinical populations. Scientists at the Neuroimaging Center have established a close and mutually advantageous partnership with clinicians at Kessler Institute for Rehabilitation: Kessler's patients are an important pool of potential research participants, and are referred to the center based on the relevance of a protocol to their treatment needs and goals. For instance, an individual who has



experienced a TBI and who is exhibiting significant problems with memory or delayed recall could participate in an investigation into a new therapy for addressing these symptoms.

Future Findings

At this time, 23 research protocols involving fMRI are active or planned at Kessler. One project, supported by the recent acquisition of a three-year grant from the New Jersey Commission on Brain Injury Research, may help improve social functioning and quality of life among individuals who have sustained a TBI. Researchers at Kessler are using fMRI along with other neuroimaging to clarify how dysfunctions in emotional processing may be related to structural and functional damage in the brain, which might inform treatments. Additionally, the New Jersey Commission on Spinal Cord Research recently funded a study through the Kessler Foundation in which fMRI will be used to help investigate whether cardiovascular dysfunction plays a role in the increased prevalence of attention, memory and other cognitive impairments observed among individuals with spinal cord injury.

The utility of fMRI in rehabilitation research is clear, and as our knowledge increases—through the use of this powerful tool—our ability to improve the lives of patients should similarly expand.



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Leading change: Celebrating 65 years in patient rehabilitation

Frank Krusen. Howard Rusk. John Coulter. Walter Zeiter. Henry Kessler. These physicians are synonymous with the field of physical medicine and rehabilitation (PM&R). Each was instrumental in PM&R being recognized by the American Board of Medical Specialties, as well as in its growth over the past century. While the contributions of these leaders in medicine are immeasurable, the vision of one man to “create a program to treat the whole individual, one that would help him or her successfully regain physical, mental, social, vocational and economic usefulness to the fullest possible degree” warrants special attention as the rehabilitation hospital that bears his name celebrates its 65th anniversary.

After World War I, a young orthopedic surgeon began a fight on a new front. As an intern, Henry H. Kessler saw firsthand that the rehabilitation of our nation’s soldiers and others with catastrophic injuries and illnesses focused solely on their physical recovery. He instinctively knew that a better, more effective model of care was needed—and found the seedlings of that at U.S. General Hospital No. 3 in Newark, N.J. The hospital, established in 1918 by Fred Albee, M.D., offered wounded veterans medical treatment along with physical and occupational therapy, vocational training, psychology and social services, and prosthetic and orthotic expertise. In the mid-1920s, Kessler brought those elements to a new, state-sponsored rehabilitation clinic for injured workers and began to advocate on a national level for the rights of individuals with disabilities.

From Advocacy to Action

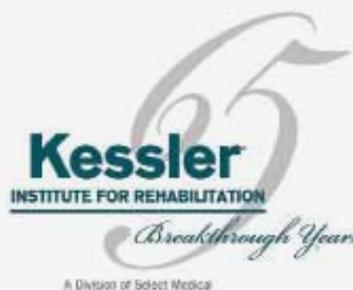
The term *physiatrist* was coined in 1938 by Krusen, a former military surgeon, to distinguish the unique focus of physicians working in physical medicine. Formal training for new physiatrists was first included in medical school curricula in 1943—the same year that Kessler, who was then serving in World War II, established the Navy Rehabilitation and Amputation Center at Mare Island northeast of San Francisco. He also brought together an

advisory board of experts in the field that, in collaboration with the federal government’s newly created National Research Council, implemented a \$5 million research program to advance the development of artificial limbs.

His military experience left Kessler, as he described it, even more “determined to focus [my] energies on enlarging the scope of post-war rehabilitation for civilians as well as veterans.” But when he returned home in 1946—just months before PM&R became a board-certified specialty—he found that the practice of rehabilitation medicine faced substantial operational and bureaucratic challenges. Despite this, Kessler persevered and, in 1948, with the support of local community and business leaders, he purchased a small, two-story brick building on a hillside in West Orange, N.J., for \$125,000. On Jan. 4, 1949, the first patients were admitted to the 16-bed Kessler Institute for Rehabilitation.

Henry Kessler assembled specialists to provide the comprehensive services

The interdisciplinary team model that Dr. Kessler helped to create remains the industry standard for the delivery of quality rehabilitative care. — BRUCE POMERANZ, M.D.



BEDS AND BENCHMARKS

To support the changing needs and increasing demand of patients seeking its services, Kessler Institute for Rehabilitation has grown from a 16-bed hospital in West Orange, N.J., to a 336-bed network on three campuses with more than 85 outpatient centers in the state today. The original West Orange hospital, which underwent several expansions, now accommodates 152 patients. The addition of the 72-bed Chester campus in 1989 and the 112-bed Saddle Brook campus in 1993 brings the current complement of beds to 336. But more important than physical capacity is the growth of Kessler’s specialized programs and services, including urology and fertility, cognitive rehabilitation, driver rehabilitation, wheelchair seating and mobility, a spina bifida clinic, and cardiac recovery—all of which attest to Henry Kessler’s belief in treating the diverse needs of every patient.

Dr. Kessler was a unique role model. His balanced devotion to patient care and research set the stage for us to pursue our own multifaceted goals in this field.

— CRISTIN MCKENNA, M.D.

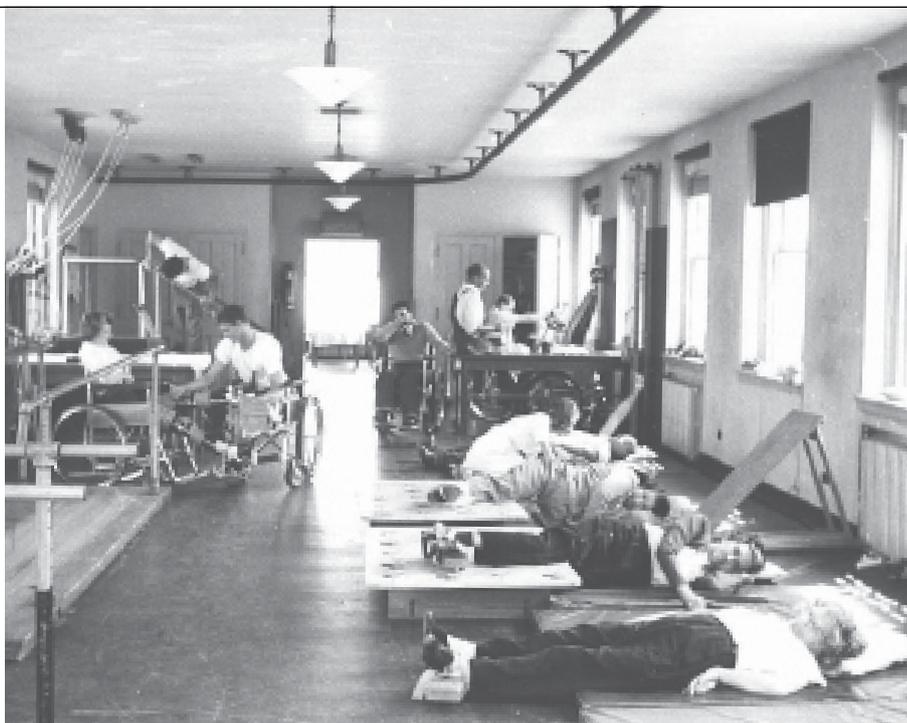


patients would require; together they set forth to achieve the hospital's fivefold mission: patient care, community education, training of rehabilitation personnel, research, and international outreach. But patient care always came first.

Removing Boundaries

Responding to the needs of veterans, as well as individuals affected by work-related impairments, polio, spinal cord injury, brain trauma, stroke, amputation and other neurological and orthopedic conditions, Kessler and his team began to implement new programs, explore fresh avenues of treatment, enlarge the hospital and extend its geographic reach. Within a decade, more than 600 patients were being treated annually. Today, the hospital treats nearly 7,000 inpatients each year across its three campuses.

Research was—and still is—a driving force not only in the delivery of safe, quality care and patient outcomes, but also in the overall advancement of the field. It was similarly of primary importance to Henry Kessler. His research with amputees,



for example, led to significant changes in prosthetic design and manufacture that offered greater function and maintained better skin integrity.

In 1954, with the passage of the landmark Vocational Rehabilitation Act Amendments, Kessler Institute for Rehabilitation received a \$90,000 grant to establish one of the first pre-vocational diagnostic programs in the country, which helped to prepare thousands of individuals to return to work, school and the community.

The institute later collaborated with the New Jersey Bell Telephone Co. on the development and use of a voice-activated phone. Today, Kessler Institute for Rehabilitation, in collaboration with the Kessler Foundation, continues to be at the forefront of research as one of only eight federally designated Model System centers for both traumatic brain and spinal cord injuries.

Training for Tomorrow

Henry Kessler was a lifelong learner. Although he had retired from active practice in 1969, he was proud that New Jersey's first residency program in PM&R was established at Kessler Institute for Rehabilitation in 1975 in affiliation with the University of

Dr. Kessler taught us that compassion is as important in the care of patients as diagnostic skills and treatment modalities.

— STEVEN KIRSHBLUM, M.D.

Medicine and Dentistry of New Jersey Medical School (now Rutgers, New Jersey Medical School). In addition, clinical training programs for nurses and therapists were implemented in collaboration with several area colleges.

Until his death in 1978, Kessler traveled the world, educating practitioners and the public about the importance of integrating PM&R into a nation's health care system. But his legacy and the work—or challenge—that he handed down to those who today follow in his footsteps are perhaps best summed up in his own words: *"Rehabilitation is the unfinished business of the medical profession and the community. It is more than the rebuilding of shattered lives. It is a fierce belief in our individual responsibility for what happens to our fellow man."*

It is to that responsibility we hold fast today.

Establishing a framework for measuring safety and quality

> BY BRUCE M. GANS, M.D.

THE APHORISM “if it isn’t measured, it can’t be managed” rings true today. Managing by measuring is the modern administrative approach. When it comes to safety, however, analyzing everything is not necessary. It is important to decide what data need to be gathered based on the anticipated output and the type of decisions to be made.

Some things are easy to track, but that doesn’t make them important. For example, central-line associated bloodstream infections and catheter-associated urinary tract infections are now mandatory Medicare quality reporting measures for inpatient rehabilitation hospitals/units (IRH/Us). While these are important infections in general, rehabilitation hospitals have a low incidence of these events compared with acute care hospitals. These measurements are required by Medicare as part of its attempt to harmonize calculation methods across the continuum of care.

Many would argue that these factors are not likely to be truly representative of what constitutes quality or threats to quality of care in an IRH/U. They may represent, instead, measures of administrative convenience rather than of prime significance to our care delivery system. Safety and quality tracking should be relevant to the care setting.

Evaluation Frameworks

The current quality domains are based on the Donabedian model, introduced nearly 50 years ago. This provided a foundation for examining the quality of health care services by evaluating three factors: structure, process and outcomes. Structure included the facilities, equipment, staff and resources; process applied to the interactions between the patient and staff; and

outcomes were the effects of health care on the patient and society.

Over the years, variations of the model have been developed that apply to different clinical settings and patient conditions, but the original version is still relied upon as the primary one for health care. In reality, the Donabedian

model is not robust enough for the priorities of rehabilitation. Most acute care settings have operationalized their quality programs, not by tallying positive outcomes, such as the recovery of a patient in rehabilitation, but rather by counting negative events, such as mortality or infection rates.

From a rehabilitation and social policy perspective, a better approach would be to focus attention on themes that are specific to the goals of a given care setting.

From a rehabilitation and social policy perspective, a better approach would be to focus attention on themes that are specific to the goals of a given care setting. For IRH/Us, we propose six themes that are worthy of consideration and measurement: 1) adverse events; 2) positive health improvements; 3) functional improvements; 4) patient expectations; 5) efficiency and effectiveness; and 6) durability and sustainability of health and functional gains.

The tracking of *adverse events* is widely expected, and must be included in any health care safety model. *Positive health and functional improvements* represent the goal of rehabilitation hospitalization and demonstrate the benefits of such treatment. *Patient expectations* and perceptions are frequently assessed, but little attention is paid to how they are managed as

compared with the extent to which they are met. For example, if you predict that a patient will not be able to perform a certain task and the individual accomplishes it, everyone is happy. Setting relatively low expectations that the patient exceeds may boost confidence and satisfaction.

In terms of *efficiency and effectiveness*, the current intense focus of public policy on prudent stewardship of resources is widely held as an expectation of those who pay for medical care. Measuring or describing the cost-benefit and/or cost-effectiveness could be considered as a means of addressing this domain.

The *durability and sustainability of health and functional gains* consider whether the patient’s improvement was maintained or exceeded after discharge. Medicare is measuring 30-day readmission rates in acute care hospitals, and recently announced doing the same for IRH/Us. Prudent organizations will try to identify an appropriate gauge of the long-lasting nature of the care provided, to both judge and defend what is being done for patients.

IRH/Us are urged to review their quality and safety measures to see which of these themes are being addressed adequately and which are not. Strategic planning and considerable thought can help ensure that the most important factors are being observed and managed—not just the easiest ones.

Rehabilitation for spinal cord tethering facilitates functioning in spina bifida patients *(continued from page 1)*

Even though spinal closure for spina bifida usually occurs during infancy, some children who develop a tethered cord might be symptomatic relatively quickly, whereas other patients might not be affected until adulthood (see “Not Just a Number”). As children enter adolescence, the spinal column stretches, and the cord becomes increasingly taut, typically causing unseen symptoms to surface. The development of a tethered cord in adults without spina bifida can be associated with microtrauma caused by repetitive, normal spinal motions (flexion and extension), which, over time, increase traction. In some cases, neurological impairment may manifest in adulthood after pregnancy, childbirth or severe back injury.

though, is the degree to which surgery can reverse these and other neurological problems; this is where postoperative rehabilitation plays an important role.

After Surgery

Kessler's Spina Bifida Services is a cross-disciplinary program that integrates physiatry, urology and neurosurgery with physical, occupational and recreation therapies, as well as other areas of rehabilitation medicine, to address associated impairments, irrespective of whether spinal tethering is present.

The primary goals of rehabilitation specific to those who have undergone detethering are to 1) help restore motor, sensory, bowel and bladder functioning to baseline levels; 2) increase the individual's ability to engage in activities of daily living independently; 3) enhance or preserve quality of life as much as possible; and 4) address pain linked to tethering or postsurgical pain. Gait training can address ambulation problems and improve balance, for example. Bowel

NOT JUST A NUMBER

The age at which someone with a tethered spinal cord becomes symptomatic is a key factor in the patient's clinical profile and informs what types of disturbances may appear. Compared with adults and adolescents, young children less frequently note pain as their predominant symptom and are more likely to experience sensory and motor difficulties, including impairments in walking or running. Regression of bladder or bowel function can occur, but in toddlers should be differentiated from normal behavior associated with toilet training. Adult-onset tethering, on the other hand, is more often linked to pain and sphincter dysfunction as the primary clinical indicators, rather than sensorimotor manifestations.

The success rate of this “detethering” procedure is high in terms of preventing further decline in condition or aggravation of symptoms.

Unclear Outcomes

Without treatment, further deterioration of the spinal cord can occur, though this is not inevitable. Discrepancies in symptom presentation mean that not all patients will require treatment. When tethering is not causing significant impairment in sensory or motor functioning, like ambulatory difficulty, intervention may not be needed unless that status changes.

Once that occurs, or if a high level of disability is already present, surgical removal of the scar tissue, which liberates the cord, is pursued. The success rate of this “detethering” procedure is high in terms of preventing further decline in condition or aggravation of symptoms—particularly as related to pain, motor decrements and bladder incontinence—although retethering can occur. What is less predictable,

and bladder stabilization programs facilitate management of incontinence and prevention of urinary tract infections as well as future kidney problems. Physical and occupational therapies attend to muscle tone and strength. Starting these interventions as soon as possible after detethering increases the chances for optimal recovery.

Many of the patients at Kessler who have experienced rehabilitation following cord release were participating in the spina bifida program preoperatively, allowing for continuity of care. In some

cases, postsurgical complications can impact existing treatment plans. Leakage of cerebral spinal fluid, for instance, may lead to headaches and positional instability, which can hinder mobility training and balance. Individuals who continue to report pain after detethering may require medication that could affect bowel and bladder functioning, potentially complicating preoperative bowel and bladder programs.

The long-term prognosis of surgery and rehabilitation is highly individual and depends largely on the types of deficits and degrees of severity. However, even in the absence of full symptom reversal, the combination of the two appears to effectively increase the likelihood of patients reestablishing independent and fulfilling lives.



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Safety and quality: Summit takeaways

➤ **BY BRUCE POMERANZ, M.D., MMM, AND JOAN ALVERZO, R.N., CRRN, PH.D.**

ANTICIPATION CHARGED

the air as the First National Summit on Safety and Quality for Rehabilitation Hospitals kicked off on May 20, 2013, and the sessions did not disappoint. The keynote addresses, especially the emotional personal experience of Sorrel King, reinforced the need for communication and focused the spotlight on safety.

In addition to the keynotes, many best practices were included in breakout sessions. One such example was the Wound Care Champion program that started with a small group of nurses trained in the prevention, treatment and healing of wounds. As these experts began working with patients, the staff nurses also became engaged and developed their own competence. Since initiating this idea at Kessler Institute for Rehabilitation three years ago, the prevalence of wounds has decreased. The results have also been positive at Baylor Institute for Rehabilitation, where the program began last year. This presentation demonstrated how a little expertise and a change in interaction can affect

patient care, and how the team can drive best practices.

Presentations from both Kessler and West Gables Rehabilitation Hospital illustrated how to reduce acute care transfers (ACTs) by increasing awareness. The focus was on improving the rehabilitation hospital's capacity to detect changes in a patient's condition early. By increasing staff knowledge, monitoring more vigilantly, and improving care for those with medical concerns, adverse events can be identified and treated sooner. Not only has this reduced the rate of ACTs, but functional improvement and the discharge rate to the community have also improved.

West Gables shared its successful "fireman" initiative, intended to improve the patient experience. The fireman is an advocate who visits every patient regularly, getting to know their likes and dislikes, working to keep them satisfied and "putting out the fire" before a situation escalates. As a member of the leadership team, he immediately brings forward issues and suggests corrective action. He also

adds a personal touch. For example, if a patient changes rooms, flowers and a card are in the new room waiting to welcome the individual.

Another best practice was the WOW Discharge program at Magee Rehabilitation, which helps to manage the biggest challenges faced during a transition of care. Also, Emory University's approach to measuring team function among the general rehabilitation and stroke patient populations can be used to predict outcomes and provide useful information for process improvement.

Each of the 24 breakout sessions during the two-day summit provided ideas and strategies to improve quality and safety. Feedback was so favorable that an annual event is under consideration.



Slides from each presentation are available at: safetyqualitysummit.org or scan the code at left.



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