

Lessons Learned Through Leadership

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What is leadership? To create something new and bring it to fruition? To carve a path for others to follow? To see the future before its time? Fortunately, my career in physical medicine and rehabilitation (PM&R) has been all that and more. My personal philosophy is to understand function and to measure it so as to ultimately improve the patient's quality of life. My career has had fundamental challenges and great opportunities, which I can summarize as follows:

- Convincing PM&R clinicians to recognize both the importance of measurement and measuring the results of their efforts.
- Helping clinicians understand scientific measurement of latent traits, including functional independence, pain, and quality of life.

LOOKING BACK: A UNIQUE PERSPECTIVE

Having been elected president of the American Academy of Physical Medicine and Rehabilitation in 1975, I had the unique advantage of serving at approximately the midpoint of our 75-year history. When I completed my residency, physiatry was just 20 years old. Upon assuming office, I had practiced for 17 years. During my term in office (1975-1976), our nation was busy celebrating its bicentennial and the independent living movement was gaining steam. The 38 years that followed were to be among the most productive and life changing of my career. As we celebrate our 75th anniversary, I am proud to recall the challenges we faced and how our specialty and its leaders grew.

EDUCATION AND TRAINING

I am a third-generation African American physician. My father was a physician, as was my grandfather. I expected to be a general practitioner. After graduation from New York University School of Medicine in 1952 and a year of internship at a Long Island, New York, hospital, I joined my father in general practice. Within a year, however, I was drafted into the army. While in the military, I chose to pursue a 3-year residency training in PM&R at Walter Reed Army Hospital in Washington, DC. I accompanied the internist, neurologist, orthopedic surgeon, and rheumatologist on their rounds and perceived PM&R to be the general practice of the specialties. After Walter Reed, I transferred to the Letterman Army Hospital in San Francisco, where, upon completing my military commitment, I was honorably discharged with the rank of major.

CHALLENGES FACED

Once out of the service, I accepted a position as a physiatrist at Yale University School of Medicine and Yale-New Haven Hospital, where I practiced for 7 years. In 1968, on the recommendation of Frank Krusen, MD, I was offered and accepted a position as department chief of rehabilitation medicine at Tufts University in Boston, where I stayed until 1976. This was the time when problem-oriented medical records and SOAP (subjective, objective, assessment, plan) charting as well as team conferences were prevalent. Each of the clinical therapists (PT, OT, SLP), along with nurses, social workers, dieticians, and resident physicians were expected to write complete SOAP notes on every patient. As director, in preparation for patient team conferences, I read and commented on their SOAP notes, which was much too time consuming. While sitting in my office, surrounded by

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piles of paper charts, I said to myself, "There has got to be a better way." We were a team in name only. After reading all those notes, it was apparent that we were silos of separate bits of information, each dutifully carrying out our tasks, each using his or her own profession's language to describe the same patients. The challenge I faced daily was: How could all that information be put together quickly to come up with a common plan of action? An answer began to take root, one that would ultimately change the direction of my career.

All patients, no matter what their diagnoses, problems, or conditions, came to our rehabilitation center in need. By using his or her special knowledge and talents, each of our clinicians provided care and treatment, so that, on discharge, patients were improved and restored to better levels of health and self-sufficiency. Although we (the clinicians), our patients, and their families, all knew the services that we provided had value, it was vague as to what that specific value was. Would it be possible to define and measure that value? I began to realize that no matter what problem or condition patients presented to us, be it stroke or spinal cord injury or hip replacement, what we did, in essence, came down to improving their functional health and independence.

Function was the common denominator; however, the word "function" could mean many different things. I came to realize universal terminology and definitions needed to be created for function, accompanied by measurement standards that every member of the rehabilitation team could understand. Not surprisingly, I was met with great resistance. I was warned by my physiatric colleagues that we did not have a reliable and scientifically based method to measure the characteristics of function as we did for other vital signs, such as blood pressure or temperature. In other words, it was not deemed possible to measure function. At that time, I did not take action toward my goal.

In 1977, I accepted a similar position at Brown University. I stayed there until 1983, when I received an offer to join the Rehabilitation Department at the State University of New York (SUNY) at Buffalo, where, at the invitation and encouragement of Glen Gresham, MD, I would now have the opportunity to pursue measurement of function.

CHALLENGES IN THE EARLY 1980s: DIAGNOSIS-RELATED GROUPS AND THE COMING OF PROSPECTIVE PAYMENT

In the early 1980s, the Health Care Financing Administration (today known as Centers for Medicare and Medicaid Services) implemented new cost controls on hospitals by presetting reimbursement levels for diagnosis-related groups (DRGs). Initially, inpatient rehabilitation facilities were exempt from the new regulation, but I knew it was only a matter of time before rehabilitation would be similarly affected. Medical rehabilitation was the low-hanging fruit on

the tree. Rehabilitation can be a resource-intensive, time-consuming, and costly endeavor; if we did not come up with a way to measure and prove the value of what we were providing for our patients, we would be at great risk to lose reimbursement for our services. We needed to find a way to measure the value of what we were doing. We needed to measure the unmeasurable. We began the work of defining and measuring function.

CREATION OF THE FIM[®] INSTRUMENT AND A UNIFORM DATA SET FOR MEDICAL REHABILITATION

With sponsorship from the American Congress of Rehabilitation Medicine and the American Academy of Physical Medicine and Rehabilitation, Byron Hamilton, MD, PhD, and I, along with key representatives of the rehabilitation community nationwide, formed a task force to develop a uniform data set for medical rehabilitation. Our goal was to develop a minimum data set that would be appropriate, to include only key patient functional attributes, those that were common and useful, that would be discipline free and acceptable to clinicians, administrators, and researchers. The task force also had to create a rating scale to measure the items. Finally, the tool, ultimately called the FIM[®] instrument ("FIM") (Uniform Data System for Medical Rehabilitation [UDSMR], Amherst NY) had to be designed to be administered quickly and consistently, and demonstrated to be a valid and reliable measure. The FIM instrument would be used to track a patient's level of function and functional independence from the initiation of inpatient rehabilitation hospital care through discharge and follow-up. Periodic reassessment would measure changes in patient performance over time and would provide data to determine rehabilitation outcomes.

The task force reviewed 36 published and unpublished functional assessment instruments, including the Barthel Index, to identify potential items and rating scales. Initially, the task force planned to only include physical functional items but, after much discussion and review, determined that it was essential to also include cognitive functional items. It was reasoned that, in some cases, cognitive factors could be as responsible or even more responsible for dependency than physical factors. The items selected for the FIM instrument assessed self-care, sphincter control, transfers, locomotion, communication, and social cognition. Although initially a 4-level rating scale was proposed, ultimately a 7-level rating scale was adopted to allow for improved sensitivity and tracking of functional changes of patients in rehabilitation.

The National Institute on Disability and Rehabilitation Research of the U.S. Department of Education provided support by awarding a grant to the Department of Rehabilitation Medicine, School of Medicine and Biomedical Sciences, SUNY at Buffalo to develop a system to document, in a uniform fashion, the severity of a patient's disability and

the outcomes of medical rehabilitation. Demographics, diagnoses, impairment groups, and lengths of rehabilitation inpatient stays were to be included in the uniform data set. Under the 3-year grant, pilot, trial, and implementation studies of the FIM instrument were conducted as well as studies to improve the clinical and technical features of the data set.

There was a significant amount of interest in the FIM instrument and the uniform data set from the start. Clinicians began using the FIM instrument to track patient functional outcomes in their own facilities and sent their FIM data for analysis, at first by U.S. mail, later by fax, and then years later via floppy discs. As information poured in, a better solution was needed; a not-for-profit organization called the "Uniform Data System for Medical Rehabilitation" was established at SUNY Buffalo in 1987 to handle FIM instrument licensing and data management. In 1988, rehabilitation facilities were given an opportunity to formally subscribe and send their FIM instrument patient records to UDSMR, and, in turn, receive back summary reports. Later, aggregate reporting and benchmarking were added so that rehabilitation facilities could compare their outcomes against other facilities in their region as well as the nation. As the number of subscribers and the size of the database grew, it became apparent that functional assessment and outcomes measurement could become a science through demonstrations of consistency and predictability. Annual data summaries were published in the *American Journal of Physical Medicine and Rehabilitation* beginning in 1992. Additional tools were developed: the WeeFIM[®] instrument (UDSMR) for children and the LIFEwareSM System (UDSMR) for outpatients. Because rehabilitation clinicians worldwide expressed interest in using the FIM instrument to track outcomes in their respective countries, UDSMR provided educational training and licenses for its use abroad, such that today the FIM instrument is used in more than 20 different countries. UDSMR's mission and vision statements can be found at http://www.udsmr.org/WebModules/UDSMR/Com_Mission.aspx.

INTRODUCTION OF THE INPATIENT REHABILITATION FACILITY PATIENT ASSESSMENT INSTRUMENT (IRF-PAI) AND THE PROSPECTIVE PAYMENT SYSTEM FOR INPATIENT REHABILITATION SERVICES

Long after DRGs were first introduced to our nations' hospitals, the Centers for Medicare and Medicaid Services in 2002 established an inpatient rehabilitation facility prospective payment system (IRF-PPS). This followed several years of study conducted by the RAND Corporation (Santa Monica, CA), which demonstrated a relationship between admission FIM ratings and the length of inpatient rehabilitation stay. Given RAND's research findings and after much input from the rehabilitation industry, the Centers for

Medicare and Medicaid Services were provided with a royalty-free license to incorporate the FIM instrument into the Inpatient Rehabilitation Facility Patient Assessment Instrument (IRF-PAI) to serve as the basis of the IRF-PPS.

2014: WHERE WE ARE TODAY

Nationwide, health care is becoming increasingly complex, expensive, and difficult to manage. In medical practice, particularly for patients who experienced a traumatic event, disability, or chronic health condition, latent traits of functioning are playing an incompletely understood and disguised role. References to latent traits appear in some legal publications but are sparse in psychology literature and almost completely absent in the medical literature. Somewhat encouraging is the increased interest in obtaining questionnaire responses and reactions from patients in terms of important aspects of their physical, mental, emotional, and social well-being, otherwise known as patient-reported outcomes. These latent traits are invaluable attributes of functional health and quality of life.

When managing patients with chronic health conditions, it is desirable but challenging to

- accurately and usefully measure latent traits and their effects on the person,
- be aware of potential conflicts associated with the person's values and preferences,
- promote quality of life by optimizing functional health.

Presently, medical practice presumes that "the physician knows what is best for the patient." I contend that we must progress from practicing the art of medicine and transform into a science with respect to measuring latent traits, by using precision case management to achieve our outcome goals.

LOOKING FORWARD: STRATEGIES FOR THE FUTURE

The slippery slope of psychiatric practice is acknowledging and strategically dealing with latent traits, which, up to this point, have been considered to be unmeasurable.

I advocate the following for achieving patients' outcome goals:

- (a) To manage health care for a patient with a chronic condition, latent traits of functional health must be measured in a uniform way, with calibrated methodology, not just described. These methods need to be responsive to individual patients, not groups or populations.
- (b) Using patient's self-reported evidence of functional health contributes to precision case management. It facilitates the physician's interpretations of the status of the patient's situation in terms of the outcome goals.
- (c) My continuing objective is to develop the self-reported evidence and other tools as accurate, trustworthy and

strategic representations of quality of life for patients with chronic health conditions and/or disablement. Use of the techniques of Rasch analysis yields information about latent traits that is measurable, strategic, and meaningful in terms of the patient's sense of fulfillment. Rasch analysis is the necessary statistical tool; a minimum list of its features includes:

- calculated intervals between items in terms of logits (log-odds) to create even steps between the levels of assessment,
- a reduced error of measurement that facilitates precision,
- hierarchical items that are calibrated each with an assigned threshold level between 0 and 100, and
- all items have a single shared dimension.

An important goal for the physiatrist is to discover the underlying mechanisms and variables of functional health. Linear measurement with Rasch models opens the window to these insights.

MESSAGE TO FUTURE GENERATIONS OF PHYSIATRISTS

- The need for rehabilitation medicine will increase. The number of Americans turning 65 years old each day grows by approximately 10,000 [1]. As consumers age, they experience chronic diseases, weakening and failing parts of their bodies, pain, limited mobility, and limited function, all that require the specialized help of physiatrists.
- The very first White House Conference on Aging in 1961 concluded that "Rehabilitation is the only hope for older people who are afflicted with disability caused by chronic or degenerative conditions until such time a specific means is found to prevent or cure them" [2].
- The next White House Conference on Aging is scheduled to take place in 2015. Let it be a call to action for PM&R physicians to actively participate and take a stand to influence the future of our nation, not only for aging Americans but for recognition of our specialty and all that PM&R does to improve the quality of life and health for everyone.

HIGHLIGHTS OF MY CAREER AS A LEADER

- Co-creator of the FIM instrument, the "gold standard" for measuring function and functional independence of patients in rehabilitation in the United States and throughout the world.
- Created uniform language to describe "functional independence," which enables rehabilitation clinicians to work as a team to achieve collaborative goals.
- Founder and executive director of UDSMR, established October 1, 1987.
- Executive director of the Center for Functional Assessment Research.
- Named most cited author among the 100 top-cited articles published in rehabilitation journals between 1959 and 2002; coauthored 10 of the 100 top-cited articles and was first author of 5 articles [3].
- Put PM&R at the forefront of tracking outcomes in medicine by establishing the world's largest, most advanced, and sophisticated rehabilitation outcomes database, which today contains more than 13 million patient assessments.
- Through analysis of that database, created some of the first "evidence-based" rehabilitation outcomes reports to guide patient care and rehabilitation treatment.

MY PRINCIPLES

- As we function, so shall we live.
- One size does not fit all.
- You cannot manage what you do not measure.

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