JAMES J. PETERS MEMORIAL LECTURE

Carrying the Torch: A Call to Build on the Progress of the Past 25 Years

Rory A. Cooper, PhD

Human Engineering Research Laboratories, VA Pittsburgh Healthcare System, Pittsburgh, Pennsylvania

INTRODUCTION

James J. Peters was a remarkable person who made many important contributions toward improving the lives of people with disabilities. The world is a more friendly, accessible, and understanding place because of the work of Mr. Peters and his contemporaries. However, much remains to be done, and vigilance is required to retain the foothold that has been gained. Contemporary changes in health care may place people with spinal cord injuries (SCIs) in jeopardy. Some of the problems, opportunities, and exciting accomplishments will be presented.

Basically, people with SCI are able to live longer and healthier than at any time in history (1). Our understanding of SCI has resulted in the creation of a medical subspecialty; this has helped to improve the acute and long-term care of people with SCI. This is certainly a step in the right direction, but clearly not enough. Quality of life (QoL) and community participation are the expectations that have resulted from improved health. It is the individual with a disability and his or her family who must and will define QoL. We need to recognize the value of QoL as a society, and the leadership in this effort must come from the community of people with disabilities and the professionals who work with them. An important measure of QoL is community participation, which has been recognized by the International Classification on Function (2). Skills and supports to enhance QoL will be determined, and their effectiveness will be reported by the person receiving the services. We must determine whether goals and desired outcomes have been met through satisfaction data collected from the people and their families.

Please address correspondence to Rory A. Cooper, PhD, Human Engineering Research Laboratories (151-R1), VA Pittsburgh Healthcare System, 7180 Highland Drive, Pittsburgh, PA 15206; phone: 412.365.4850; fax: 412.365.4858 (e-mail: rcooper+@pitt.edu).

Dr. Cooper is Distinguished Professor and FISA/PVA Chair, Department of Rehabilitation Science & Technology, University of Pittsburgh and Director and Senior Career Scientist, Human Engineering Research Laboratories, VA Rehabilitation Research and Development Center, VA Pittsburgh Healthcare System, Pittsburgh, Pennsylvania. This article is based on the author's invited lectureship at the 51st Annual Conference of the American Paraplegia Society, Las Vegas, NV, September 6–8, 2005.

Figure 1. On September 26, 2005, the Bronx VA Medical Center was renamed the James J. Peters DVA Medical Center in honor of his lifelong advocacy for veterans and people with disabilities.

LESSONS FROM OPERATION ENDURING FREEDOM AND OPERATION IRAQI FREEDOM

We are in the midst of a unique era. The United States armed forces are involved in ongoing battles in Operation Enduring Freedom (OEF) and Operation Iraqi Freedom (OIF). More than 15,000 soldiers have been injured since 2001, with approximately 10% requiring rehabilitative care (3). The eyes of the world are watching how these soldiers are faring during and after their rehabilitation.

The Department of Defense (DoD) and Department of Veterans Affairs (VA) are working at unprecedented levels to try to provide the best care available (4). The entire field of medical rehabilitation is also under tremendous scrutiny. The field has received attention in major daily newspapers and even in the widely read *Doonesbury* cartoon strip (3). Some of the programs being created by DoD and VA to address the needs of OIF/OEF wounded soldiers need to be examined as possible models in the civilian sector.

In previous military conflicts, there was no specific program to seamlessly transition severely injured soldiers into the VA. Veterans had to present themselves and prove their eligibility. For severely injured veterans of OIF/OEF, there are VA social workers within Walter Reed Army Medical Center and Brooke Army Medical Center (5). We have learned from the Vietnam War and the Gulf War that follow-up is critical. After the Vietnam War, post-traumatic stress disorder caught people off guard, and Gulf War syndrome was an unexpected outcome of the Gulf War. At this point, no one knows what the long-term effects of OIF/OEF will be on its veterans. Thus far, the evidence seems to indicate that improvements in body armor and upgraded vehicle armor have saved lives but possibly resulted in higher incidences of disabling wounds (5). The medical care starting at the battlefield through rapid evacuation through Landstuhl Army Hospital or Rota Naval Hospital brings severely injured soldiers to Walter Reed Army Medical Center or Bethesda Naval Medical Center within a few days (3). Soldiers with SCI are stabilized and transferred to a VA SCI Center for rehabilitation. The challenges in rehabilitating these soldiers are substantial, because many have experienced blasts and have multiple injuries.

The Military Severely Injured Joint Support Operations Center (MSI-JSOC) is charged with providing support to soldiers and families 24 h/d for 7 d/wk (5). MSI-JSOC involves all branches of the armed services, the VA, the Department of Labor, and various veteran service organizations. Paralyzed Veterans of America (PVA) is a key organization for veterans with SCI. MSI-JSOC brings both government and private sector resources to assist severely injured soldiers in adjusting to the wounds and reintegrating with their communities. Counseling, vocational services, recreational therapy, medical care, and other forms of assistance are available. To expand access to these services, the Military One Source Program provides referral sources 24/7 through 1-800-342-9647. The VA Vocational Rehabilitation and Education Program works closely with DoD to offer a 5-step program: rapid access; re-employment; self-employment; independent living; and long-term services (education and training). The most remarkable aspect of the DoD/VA programs is that they attempt to provide coordinated comprehensive services.

Let us examine the example of the Army Wounded Warrior Program (AW2) (5). There are 3 essential phases

that mark milestones in the process for severely injured soldiers. Phase 1 is marked by evacuation and notification. When soldiers enter the armed forces medical care channels, family are notified and a needs assessment is conducted. Phase 2 focuses on medical care for the soldier with SCI, medical board evaluation, and military retirement. Contact with the VA is established, initially through VA social workers within armed forces medical centers, and information on veteran's service organizations (VSOs) is made available. Army physiatrists are critical members of the rehabilitation team and of the medical board evaluation. Phase 3 shifts toward retirement and the long-term well being of the soldier and his/her family. Within the first 30 days of retirement, the soldier receives a visit from his/her former unit, a needs reassessment is conducted, and a representative will help to advocate for the soldier or family as necessary. After an additional 120 to 180 days, the sponsor unit will visit again, and the goal is to enroll the soldier in school or vocational training or to have the soldier return to work. The VSOs are important for providing support within the soldier's hometown. AW2 plans to follow OIF/OEF wounded veterans for 5 years to assist them in becoming contributing members of their communities.

United Spinal Association has been extremely helpful in supporting OIF/OEF wounded service members. United Spinal Association created the Wounded Warriors Project that provides comfort items to wounded service members while they are within an armed services medical center. The Wounded Warriors Project supports soldiers in long-term rehabilitation with supplies (backpack program), benefits, counseling, and access to sports programs for athletes with disabilities. United Spinal Association has also hired several OIF/OEF veterans to assist with education, advocacy, and member benefits activities.

Paralyzed Veterans of America is actively assisting OIF/OEF veterans through a number of programs. Whenever possible, PVA members and staff visit veterans with SCI who are in armed services medical centers or they catch up with them within the VA. They provide information and help to explain benefits to service members and their families. PVA has also distributed copies of the SCI Clinical Practice Guidelines to armed services medical staff. The PVA/VA National Veterans Wheelchair Games (NVWG) are an important aspect of rehabilitation for many veterans with SCI. The NVWG allow the wounded veterans to experience healthy recreational outlets, to learn adaptive strategies from experienced veterans, and to test skills. PVA provides financial assistance for OIF/OEF veterans to participate in the NVWG.

Individuals active in the rehabilitation community can do several things to assist OIF/OEF veterans with SCI. Most important is to inform veterans and their families of the services available to them and of the pluses and minuses of their choices; educate veterans about the

impact of various technologies or systems, and assist the veterans and his/her family in assuming the locus of control so that they can manage their health care. It is important to emphasize periodic follow-up at least annually and to make peer support available. Most importantly, we can facilitate employment or furthering of education.

By no means are all things ideal within VA/DoD. The Veteran's Health Administration budget remains stretched to meet the demands of currently eligible veterans and is likely to be inadequate for the nearly 2,000,000 OIF/OEF veterans. VA research funding has not kept pace with the demands placed on the investigators because of the needs of aging Korean War and Vietnam veterans and the new injuries of returning OIF/OEF veterans. It is time to evaluate government and private sector SCI health care services and research funding.

TROUBLED SCI HEALTHCARE POLICY

The basic premise of US health care policy toward people with SCI is flawed, and the trends are alarming. Much of US health care policy is focused on curing diseases, acute care, and rapid treatments (6). SCI health care policy is largely based on the antiquated idea that the lives of people with SCI are not worth living, and medical science has yet to find a cure. In addition, health care policy decisions tend to be made on the basis of the desires of large and vocal political blocks and on the demographics of Medicare beneficiaries. People with SCI are a small portion of the population and are vulnerable to cut-backs being implemented to control health care costs. In epidemiologic-based health care policy, people with SCI represent a small percentage of the population with higher than average per capita costs. This approach has little regard for the potential of people with SCI to contribute to their communities and the impact health care has on QoL.

To control costs, insurers have pressured rehabilitation centers to reduce lengths of stay, which has resulted in people with SCI being discharged without the skills needed to participate in their communities (2). In acute medical rehabilitation, there is an overdependency on the functional independence measure, which penalizes people with SCI undergoing rehabilitation (2). More people are being discharged to skilled nursing facilities instead of their homes within the community (7,8). Many medical rehabilitation facilities rely too heavily on Press-Gainey to measure perceived quality of care. SCI is often viewed as a singular event rather than a life-altering event that is dynamically changing over the life span. This has resulted in people being discharged with inadequate wheelchair skills, little or no drivers' training, insufficient vocational planning, and little or no recreational or sports skills. People with SCI are too often left to fend for themselves without the needed coping skills. This places undue burdens on families.

Inpatient lengths of stay need to be re-examined to ensure that people with SCI reach adequate functional and emotional levels to return to community participation. While it is reasonable and even desirable to have some rehabilitation occur on an outpatient basis, the person must be adequately prepared, and the inpatient and outpatient programs must be carefully coordinated. Rehabilitation is a lifelong process because people must adapt to their changing condition over years. Fortunately, the VA provides for veterans to receive periodic rehabilitation or skills development when needed. The private sector does not provide similar opportunities, with the exception of a few specialty centers with endowed funds. We need to promote rehabilitation of people with SCI as a lifelong activity and encourage our clients to remain connected with their SCI health care specialists.

ACCESS TO TECHNOLOGY

Most people with SCI rely on a variety of different technologies, wheelchairs, adaptive driving aides, cushions, etc, for daily living and to participate in their communities (9). Assistive devices are among the few items that we can provide to people with SCI that make a profound difference. Policy makers and regulators are in the process of revising the technology that people with SCI may receive. To curb rapidly rising costs for wheelchairs and for health care in general, schemes such as competitive bidding are being implemented. Some assistive devices can probably be viewed as commodity items, such as reaching devices and other simple technologies. However, wheelchairs are also being competitively bid, even though evidence shows the importance of fitting and tuning them for the individual (9,10). While the VA has implemented competitive bidding for some wheelchairs, veterans with SCI are exempt from this process because of the recognition of their clinical and functional needs. Other agencies should take note. In a study of individuals receiving wheelchairs through the National Institutes on Disability and Rehabilitation Research (NIDRR) model systems for SCI, it was determined that all of the people who were provided with a manual wheelchair received an ultralight model (9), consistent with recent clinical practice guidelines (11).

Unfortunately, not all people with SCI are so fortunate. Medicare's "useful in the home" criterion is overly restrictive in the way that it is currently interpreted. The Centers for Medicare and Medicaid Services (CMS) is a lead payer followed by others. CMS has proposed a number of changes to control costs and target technologies appropriate for specific individuals. CMS has proposed Rehabilitation and Assistive Technology Society of North America (RESNA)-based standards to support electric-powered wheelchair codes, which is a step in the right direction toward ensuring wheelchair quality (12). CMS has also proposed requiring that

a RESNA-credentialed Assistive Technology Provider (ATP) provide the justification for most electric-powered wheelchairs as a means of ensuring appropriate matching to the individual (10).

Part of the problem with assistive technology provision lays in the paucity of assistive technology outcomes studies, somewhat because of the inadequate funding support for such studies, and lack of understanding of the need for specialized clinical expertise, especially among insurers and nonrehabilitation medical professionals. Therapy and medicine residency programs spend too little time on assistive technology training, and this is compounded by the limited focus on assistive technology during accreditation. This results in inadequate prescriptions and specifications. Clinical education programs rely on fieldwork coordinators, who depend too heavily on experience rather than evidence. SCI-certified physicians are still rare, and while there are more than 1,500 ATPs and their numbers are growing, more are needed.

Assistive technology is best delivered using a team approach including an ATP, an assistive technology supplier (ATS), and a rehabilitation engineering technologist (RET) working in cooperation with a qualified physician. RESNA provides the ATS and RET credentials to identify knowledgeable suppliers and engineers.

RESEARCH AND DEVELOPMENT FUNDING

"Having reviewed trends in the United States and abroad, the committee is deeply concerned that the scientific and technical building blocks of our economic leadership are eroding at a time when many other nations are gathering strength." (The National Academy of Sciences) (13).

There is too little federal, state, and private funding for research, development, and deployment (14). Technology has had tremendous impact on the QoL and societal participation of people with SCI, but receives insufficient support. For example, pressure ulcers are one of the leading causes of death among people with SCI in developing countries, whereas seating technology has reduced the incidence significantly and almost eliminated the mortality in the United States. People with SCI have little influence over funding priorities, decisions, and research outcomes. People with SCI need to adopt a "nothing about us without us" attitude. To maximize the impact, people with SCI need to form partnerships with medical rehabilitation professionals. The most effective means of influencing policy is to present compelling stories along with supporting scientific data.

The "gold standard" of National Institutes of Health grants is the RO1, which is the designation of the individual investigator-initiated grants (15). The RO1 grants are those most likely to lead to breakthroughs. However, people with SCI and SCI clinicians are often not involved in setting priorities leading to requests for awards, in serving on review panels, or in participating on the council that makes the award decisions. The current environment with funding percentiles in the

teens or lower makes advocacy critical. For example, the NIDRR Field-Initiated Research Program has received in excess of 250 proposals per year in recent years but has only been able to fund approximately 10% of them. Such funding levels make it difficult to start or maintain research programs and necessitates that scientists spend more of their time preparing grants proposals.

The Small Business Innovative Research (SBIR) program provides support for new technologies. SBIR grants are awarded by many federal agencies, which make them particularly important. The SBIR program is for small businesses; however, it is critical that consumers participate in the reviews and priority setting.

There are models to consider for improving the research environment. The PVA Research Foundation makes grant awards for assistive device design and development, basic science, and clinical science. The PVA Research Foundation also partners with other organizations to award additional grants. Partnerships are one means of having greater consumer involvement in the decision-making process. The PVA Research Foundation also uses a 2-tier review process. The Scientific Advisory Board reviews grants for their scientific content and forwards their recommendations to the foundation trustees. The trustees are members of PVA as well as professionals. The trustees consider both the scientific reviews and the relevance of the work to people with SCI or dysfunction when making award decisions.

United Spinal Association supports research through grants to individual investigators and to institutions. This research and development support is often critical for enticing new investigators to the field and for supporting ideas that may not be funded by more conservative federal agencies. For example, United Spinal Association was one of the first groups to support research for a cure of SCI long before most scientists believed that there was even the remotest chance to develop a cure.

Disability and medical rehabilitation research is a QoL issue, a technology issue, and a medical care issue (16). This is a public health imperative. We need increased federal, corporate, and foundation funding, an ample pool of well-trained investigators, mentors for young investigators, and tools to measure the outcomes of our interventions (16,17).

GAINFUL EMPLOYMENT AND UPWARD MOBILITY

For people with SCI or dysfunction, employment can be rewarding and liberating. Employment brings social integration, pathways for upward mobility, and affords opportunities for improving QoL. Through employment, people with SCI can obtain the discretionary income to purchase additional medical coverage and to purchase items to expand their range of activities (eg, recreation and leisure). Work brings about the potential to exercise a voice through political and economic processes. Regrettably, the majority of people with SCI remains unemployed and live on low incomes (9). Although laws

such as the American's with Disabilities Act and the Rehabilitation Act have made headway in breaking down employment barriers, the social and attitudinal barriers remain a formidable, but not insurmountable, challenge.

TAKE CONTROL

It is time for people with SCI to lead. Forbearers like James Peters have shown us what is possible, but it is time for another generation to carry the torch and bring us into a new era where people with SCI have a substantial say in everything that affects them. People with SCI need to become physicians, engineers, lawyers, and politicians in increasing numbers to forge a future where everyone belongs and has a voice.

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