



Neuroprosthesis consumers' forum: Consumer priorities for research directions

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Abstract—The purpose of this forum was to discuss with consumers having spinal cord injury what their research priorities would be for the field of functional electrical stimulation (FES) and to explore the impact of technology in the lives of people with disabilities. Both FES users and nonusers were included on the panel. The format for the discussion was primarily question and answer, with each participant giving his or her personal response to the moderator's question. Consumer research priorities depended on the individual and his or her personal priorities, preferences, background, history, and level of injury. Common themes that emerged were independence, ease of movement, ease of control, and spontaneity. From the consumers' perspective, the focus of research to restore function ought to be based on the needs and desires of the consumer, not just on the scientifically intriguing aspects of a particular technology.

Key words: *consumer, FES, neuroprosthesis, SCI, technology.*

INTRODUCTION

The purpose of this forum was to discuss with consumers what their research priorities would be for the field of functional electrical stimulation (FES) and to explore the impact of technology in the lives of people with disabilities. Demographic information regarding the panel participants is shown in **Table 1**. The format for the discussion was primarily question and answer, with each participant giving his or her personal response to the moderator's question. Afterward, the discussion was opened up to include participation and interaction with the researchers in the audience. The panelists were all very educated individuals and most have advanced degrees and careers in technical fields. Participation was limited to individuals with spinal cord injury, primarily from North America.

The first question posed to the panel was, Can you prioritize the two to three activities that you would really like to be able to do that your injury prevents you from doing now? In other words, what do you want to do and what are the barriers to you doing that?

The answers to this question strongly emphasized quality of life issues, but each individual defined quality

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Table 1.
International FES Society 2001 consumer panel participants

Participant	Age	Type of SCI	Time since injury (yr)	Education	Work status	FES technology used
1	42	paraplegia	3	Masters in electrical engineering	Employed as an aerospace engineer	No FES
2	32	tetraplegia	9	Pursuing bachelors in computer science	Full time student	Implanted Freehand™ system
3	51	tetraplegia	23	Associates in mechanical engineering	Engineering drawing subcontractor	Implanted bilateral hand systems (1)
4	44	tetraplegia	18	Bachelors in engineering ceramic engineer	Employed as a percutaneous systems in the past (2)	No FES—had used
5	—	paraplegia	4	Bachelors in English literature	Employed as a program administrator	Surface Parastep® system
6	32	paraplegia	17	Associates in architecture	Self-employed	Implant standing system (3) No FES
7	34	tetraplegia	12	Pursuing bachelors in computer science	Student	No FES
8	—	paraplegia	—	Masters in physical therapy	Full-time student	No FES
9	—	paraplegia	—	—	Employed as executive director of an NPO	Implanted Vocare™ system

of life differently. Yet, almost everyone spoke of the ultimate goal of being able to walk again and many indicated that standing alone was not enough; it was important to be able to do things once standing. For the father of 8- and 10-year old boys, being able to run after balls in a game of catch was important. For others, it was being able to dance with their spouse, walk in the ocean waves, or even just have enough balance once standing to change an overhead light bulb, wind a clock, or cook a gourmet meal. For many, a strong desire to enjoy the outdoors without limitation was expressed. One individual even professed a willingness to do things that she was not willing to do before, like garden and weed. Being able to go camping and hiking in the woods, participate in water sports, even “write one’s name in the snow” were all things that these panelists wanted to do but were unable to because of their injury.

Another theme that emerged was the issue of time. Many of the panelists expressed frustration with the amount of time it takes to perform activities of daily living and the negative impact that this has on their lives. Even among those who had FES systems that allowed them to perform certain tasks, the way in which they performed the

task and the amount of time required remain an area of dissatisfaction. This was especially true for individuals who had very time-consuming bladder and bowel care regimens. Many yearned for a return of the spontaneity and impulsiveness they once enjoyed, to be able to just get up and do something without having to do all the planning that their injury now mandates. As one panelist expressed it, being able to live his life the way he used to in terms of rhythm and planning was a high priority.

Closely related to the issues of time and spontaneity was a common desire for more independence. Not having to wait for personal attendants and caregivers for assistance, not having to coordinate movements and activities around other people’s schedules, and being able to make a decision and act upon it immediately without considering the need for help were commonly expressed desires.

Many of the responses to this question suggested a longing to be able to socialize in ways in which the panelists were no longer able. Some spoke of a return to hobbies that afforded them those interactions with others, such as being able to hang out with friends and shoot pool or rebuild old cars. Others spoke of the fact that many of their family and friends only knew them in a wheelchair

and had never played football with them or interacted with them on a more physical level. Still others expressed how much they missed the lost sensory function—to feel a hug from a loved one and be physically comforted, or to sensually and intimately interact with a significant other.

Among the FES users, other priorities that were identified specific to their devices included miniaturizing the systems, perhaps making all the components internal and waterproof, or doing away completely with the external components (electrodes and oversized batteries and controllers). Also, a finer degree of control was important. For example, one panelist expressed a desire to be able to turn a regular doorknob so that he could visit the inaccessible home of friends, or not have to worry about safety issues in a venue that did not have lever door handles.

The second question was, If you could be provided with the ability to perform your most desired function, how much of a hassle are you willing to go through in order to get it?

All the respondents expressed some sense of balance between the risks and the benefits, although again, that balance was very individualized. Many FES applications are still experimental, and for some panelists, that was too much risk. Although they admired and respected those “pioneers” that were willing to try unproven systems, they themselves needed some guarantees. Some expressed a need for a 90 to 95 percent certainty that the system would restore the proposed function and that it would do so the first time and every time that it was used. These individuals had established a new lifestyle after injury and were unwilling to endure major disruptions or to sacrifice large amounts of time and energy if there was no guarantee of a better life. It was important for some not to have to spend a lot of time being in the hospital or learning to use a neuroprosthesis, and ideally, they preferred not to undergo any surgery.

Other panelists were willing to do whatever it takes to regain function, even working 10 to 12 hours per day for 6 to 7 days a week with no guarantee of a positive outcome. One panelist with tetraplegia who was a long-term participant in the experimental FES program simply asked the question, “How can you put a price on regaining the use of your hands?” Another user of an implanted FES system indicated that once before he had gone through the process of surgery, rehabilitation, and training, and he would go through it again if it meant possibly regaining more function.

On the other hand, having foreign materials implanted in their bodies was a line that some were not willing to cross. Among the reasons given for this limit was that spinal cord injury was not a life-threatening condition for these panelists. Having managed to adjust to their injury and carve for themselves a lifestyle of quality and personal satisfaction, many judged the risks of surgery and possible complications from chronic implantation too high relative to the potential rewards offered at this point of development in FES technology. Many consumers stated that they had become quite proficient using their wheelchair for mobility and any alternative means of mobility would have to be more efficient for them to even consider it. They were not interested in disrupting their lives for little or no practical gains. Yet, even among those with this opinion was heard the willingness to “go for it” if the outcomes could be guaranteed with some high degree of certainty.

In addition to the balance between risk and benefit, reversibility was an important consideration for some. Both users and nonusers of FES systems desired interventions that would not limit their opportunities to take advantage of future therapies that might offer even better outcomes. If a technology were thought to jeopardize an individual’s candidacy for a possible future spinal cord injury “cure,” some panel participants would not be willing to consider it. It is interesting to note that users of both external and implantable FES systems identified “reversibility” as an important feature of the systems they selected.

There was also a different “hassle factor” that the panelists were willing to endure for different functions. This again was based on individual priorities. For some, it was worth it to have surgery to regain bladder and bowel function, but not to be able to just stand and not walk. For others, no amount of effort would be too great to be able to increase their independence by being able to use their hands again, however imperfectly.

The third question asked was, What was the decision-making process that you went through when deciding to use or not use an FES technology? For FES users, how did you decide what technology to use?

Surprisingly, some of the panelists indicated that they did not use an FES system because they did not know about them until now. One participant shared that he had been in three to four different rehabilitation facilities and had talked to over 200 patients and none of them ever mentioned FES. He was in the process of doing his

due diligence to research the pros and cons of FES for his life and wondered why the technology was not more widely promoted and marketed. Another panelist, from Belgium, indicated that lack of local availability had really prohibited him from considering an FES system for himself.

For the majority of users, their decision to incorporate FES into their lives was based on the potential long-term benefits, which began to override the risks. One consumer was informed about the Parastep® (Sigmedics Inc., Wheeling, IL) system early after injury and was impressed with its potential to decrease her spasticity and consequently her medications, to increase her muscle mass, and thereby decrease her risk for decubiti, and to increase her bone density, thereby reducing the risk of fracture. The fact that she did not have to alter an established pattern of life and that the system was noninvasive and could be put on and taken off at any time was key.

For another user, recurring decubiti had really become a problem and any intervention that might limit their occurrence or severity was worth considering. Though the implanted system he now uses is still experimental, he considered the fact that he would have his own personal system and eventually not have to go to the lab to exercise a strong benefit. In addition, another important factor in his decision was that the system was provided free of charge because of its experimental nature.

Yet another panelist considered her age and level of activity and determined that she was too young and too active to allow her bladder to slow her down. She was also comforted by the knowledge that the Vocare™ (NeuroControl Corp., Cleveland, OH) device was no longer experimental, but was available commercially with proven success. But in the end, it was the trust and confidence that she had in the doctor that recommended this therapy for her that ultimately made up her mind.

This notion of trust and confidence in the provider recommending the system appeared to be an important factor for all those who used FES. Feeling well informed about the potential risks and having realistic expectations about the benefits was crucial. For one of the true pioneers of FES technology, an individual who has been involved in the research program for over 23 years, confidence that he was presented with all the facts and trust in the researcher were crucial factors in his decision to participate in the research and development of something that might help him and others in the future.

Yet, the biggest hurdle for some remained the hesitation over having foreign materials implanted in their

body. One user was able to overcome this trepidation with the help of family support. When explaining his hesitancy to his grandfather, one user was asked, "Is it going to be harder than what you went through when you first got injured?" and to which he responded "no." Then his grandfather asked, "Is it going to help you?" and to which he was able to respond "yes." Finally his grandfather asked, "Then what more is there to think about?" This objective outside rationalization of a supportive family member helped this user to overcome his fear of the surgery and get the system. This individual has now used the Freehand™ (NeuroControl Corp., Cleveland, OH) for over 5 years and reports that the system far exceeds his expectations and was well worth it.

The importance of family support was echoed throughout many of the responses. In fact, one panelist reported that he had been a user of an FES system for 15 years. However, when his support system deteriorated, he opted to remove the system because of the difficulties he was having with the electrodes and with the donning time. His decision not to replace his percutaneous system with an implanted one was based on the downtime that the procedure would require and the risk of surgery.

The final question was asked of both the consumers and the researchers present at the forum: Consider a graph of different functions on the y-axis such as grasp, arm movement, standing, walking, bladder function, etc. Consider percentage of preinjury function on the x-axis. What percent of the way to achieving these various tasks do you think we are with the current technology, and what must be done to increase that percentage to 100?

Regarding grasping, the majority of the consumers felt that approximately 40 percent of function had been achieved by the current technology. Others, including designers, did not see how the field could be 40 percent of the way to restoring this function when there was no sensation yet. Part of functional grasp is being able to sense what you are grasping and where in space your hand is. Therefore, sensation and proprioception need to be added to drive that number closer to 100 percent. In addition, muscle coordination and strength need to be increased. After much discussion, it was determined that competition, increased funding, time, and collaboration among relevant specialties were going to be needed to improve the outcomes of any FES application.

In the area of arm movement, no consensus percentage could be reached, but nearly everyone agreed that it

was far below the 40 percent achieved for grasping. A few felt the number was as low as 1 percent. One way to drive this number toward 100 percent was deemed to be the discovery of better methods of restoring innervation in muscles and the development superior control mechanisms. Some researchers felt that the reason for this low number was the lack of a mathematical model of upper-limb movement. Before investigators can develop solutions to abnormal function, it was argued that there must be a mathematical model of "normal function" to work from. Otherwise, it is not science. Others contended that an appropriate mathematical model did exist and that the problem of arm movement after SCI simply needed to be expanded to other sciences, such as biomechanics, robotics, and even mathematics.

It was generally agreed that standing has been 50 to 60 percent achieved. However, balance is still a big issue. As engineers, some researchers expressed a strong desire to be able to give the consumers what they wanted—a restoration of "normal" function. And although many were optimistic that this would eventually be possible, many were sensitive to the constraints and limitations of the current technology. Consequently, a need was identified for further basic research in order to perfect some of the FES applications. Again, the need for improved control systems was mentioned. Such systems need to be stable and able to respond quickly to determine and make necessary corrections before the body collapses. That was perceived as a difficult engineering problem to solve because the human body has many complex joints and muscles to control. Also important to solve is how a better-standing system would be controlled in tetraplegic subjects.

The challenge of achieving better controls and "normal" function suggested the potential need for a connection between the cerebral thought of performing a task and the actual motor movement. For example, if you have to move your shoulder to close your hand, that is not "normal" function. For many it is indisputably better than not being able to grasp at all, but it does not begin to approximate the level of control that existed preinjury. However, a direct brain interface for control of neuroprosthetic systems would be very invasive, which could be a considerable disincentive to many people.

Walking was deemed to be approximately 20 to 30 percent achieved. Necessary improvements include having far fewer wires and electrodes in the system and better balance and coordination. Also, a smoother gait and better energy efficiency need to be attained before that percentage can approach 100.

CONCLUSION

Consumer priorities for FES research directions depend on the individual; his or her personal priorities, preferences, background, history; and level of injury. Although this consistently holds true for FES use (4–6), this is true for users of nonimplanted technologies as well (7–10). By the researchers talking with current and potential users and allowing them to brainstorm together, the field can be advanced much more quickly.

Common themes in priorities that emerged were independence, ease of movement, ease of control, and being able to "do what you did before the injury" (especially recreational activities). In particular, the panel expressed a strong desire to have the ability to be spontaneous and to participate in new activities without a lot of preplanning and preparation. Another key feature that many panelists identified was that any intervention needed to be reversible so that the individual could take full advantage of any future "cure" for SCI. Obviously, these panelists cannot represent everyone, but the insights gained from their individual concerns contain details that might be missed in a larger survey. This particular forum was limited to participants with spinal cord injury. However, similar forums for other disability groups may prove to be very informative as well.

From a technical or research perspective, there will always be interesting questions to pursue and challenging problems to solve, but from the consumers' perspective, the focus of research to restore function ought to be on the needs and desires of the consumer, not just on the scientifically intriguing aspects of a particular technology. Soliciting the participation of consumers at scientific conferences by utilizing forums like the one reviewed in this paper can be a very effective way to establish research priorities that seek to improve the lives of individuals with disabilities in ways that are not just functional, but that are acceptable and satisfactory to the consumer.

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Kevin Kilgore, PhD, organized the panel and Marcia Scherer, PhD, moderated the panel and audience discussion.

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