

Targeting Recovery: Priorities of the Spinal Cord-Injured Population

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ABSTRACT

In the United States alone, there are more than 200,000 individuals living with a chronic spinal cord injury (SCI). Healthcare for these individuals creates a significant economic burden for the country, not to mention the physiological, psychological, and social suffering these people endure every day. Regaining partial function can lead to greater independence, thereby improving quality of life. To ascertain what functions are most important to the SCI population, in regard to enhancing quality of life, a novel survey was performed in which subjects were asked to rank seven functions in order of importance to their quality of life. The survey was distributed via email, postal mail, the internet, interview, and word of mouth to the SCI community at large. A total of 681 responses were completed. Regaining arm and hand function was most important to quadriplegics, while regaining sexual function was the highest priority for paraplegics. Improving bladder and bowel function was of shared importance to both injury groups. A longitudinal analysis revealed only slight differences between individuals injured <3 years compared to those injured >3 years. The majority of participants indicated that exercise was important to functional recovery, yet more than half either did not have access to exercise or did not have access to a trained therapist to oversee that exercise. In order to improve the relevance of research in this area, the concerns of the SCI population must be better known and taken into account. This approach is consistent with and emphasized by the new NIH roadmap to discovery.

Key words: bladder, bowel, and sexual dysfunction; consumer preferences; quality of life; spinal cord injury

INTRODUCTION

CHRONIC PARALYSIS of all forms, not just traumatic spinal cord injury (SCI), is a longterm health, economic, and social issue worldwide (National Spinal Cord Injury Database, 2001; Dijkers et al., 2000). Currently, scientists are pressured on many fronts to develop an all encompassing “cure” for paralysis. The complexity of

such an “all or nothing” approach is rather daunting, however. While the scientific understanding of central nervous system (CNS) regeneration has advanced greatly in the past twenty years, there are still many unknowns with regard to inducing successful regeneration, especially in the chronic SCI state (Filbin, 2003; Houle and Tessler, 2003; Blight, 2002; Hulsebosch, 2002; Kwon et al., 2002). A more realistic approach, if we are interested

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in improving the quality of life of a large proportion of the paralyzed population in a more expedient time frame, may be to develop treatments that lead to partial functional recovery. It is important to stress that the ultimate goal is, and should be, to “cure” paralysis, and to emphasize that treatments leading to incremental (partial) functional recovery does not take away from that goal but rather may offer a more practical and efficient path towards it.

The research field can objectively address the physiological dysfunctions associated with SCI and develop clinical treatments that yield increments of functional return that will have a profound impact on the quality of life. There are, however, differences between the human and animal SCI condition (Sipski, 2003; Carlson and Gorden, 2002; Tator, 1998). A good way to learn and understand more about these differences is to collect information from the human SCI population. By learning which issues are clinically significant, the scientific community can more effectively translate promising animal studies into carefully designed clinical trials with the goal of developing treatments that will improve dysfunctions and enhance the quality of life of a significant proportion of people living with SCI.

Previous studies have assessed the quality of life and preferences of different groups of the SCI population. In 2002, Tate et al. performed a comprehensive review of multiple such studies. Not surprisingly, people with SCI tended to report a lower quality of life than non-disabled individuals. Many of those studies indicated that factors such as access to the community, marriage, social support, and community integration have a profound impact on quality of life. Very few studies, however, have asked people with SCI what would improve their quality of life. Estores (2003) reviewed six studies and found that bladder and bowel function, sexual function, pain, and mobility were important concerns to the SCI population. In addition, Widerstrom-Noga et al. (1999) demonstrated that the above mentioned dysfunctions were perceived as difficult to deal with by persons with SCI. However, no studies could be found by the author in which people with SCI were asked how basic science research could impact their quality of life. This is a very important question in light of the multiple advances being made in animal SCI research leading to regenerative sprouting and functional recovery.

Therefore, the present study was undertaken to determine what areas of functional recovery the SCI population would most like researchers to address in order to have a positive effect on their quality of life in the near future. The data presented here demonstrate that the spinal cord injured population is interested in increments of functional recovery in a number of important domains,

depending on the injury level and with the understanding that full functional recovery is the most desired outcome.

MATERIALS AND METHODS

Survey Design

The survey questions (Table 1) were designed to determine which areas of functional recovery were most important to the SCI community. There were multiple reasons for the format of this novel questionnaire. First, the questions were intentionally designed to be short and simple so as to increase the number of participants. Second, this study was undertaken to determine which physiological functions were important to improving the quality of life of the SCI population in general. Thus, the seven categories of functional recovery to be ranked were intentionally kept broad so as to be inclusive rather than exclusive. For example, “arm/hand function” implied any recovered function of the shoulder, upper arm, lower arm, wrist, or fingers. Regaining “bladder/bowel function” was combined with the “elimination of dysreflexia.” Though these may seem like two very different ideas, one being a gain of function and the other being a loss of function, to a person living with SCI these issues are often inseparable. For example, if one were to eliminate the development of dysreflexia during a bowel movement but not improve function in the bowels (either voluntary or involuntary), this would still be considered an improvement in quality of life. The same concept holds true for the “elimination of chronic pain.” For even though that is not a gain of function, the loss of aberrant sensation would have a dramatic improvement in the quality of life. “Walking movement” included any type of movement of the lower extremities, such as walking or standing with or without assistive devices, body-weight supported treadmill locomotion, or swimming pool based exercise. The term “walking” alone was not used in order to prevent “walking” being equated with “cure,” which is a common, yet understandable, misconception by a small number of people living with SCI who may not understand the complexities underlying regeneration or who, more importantly, do not have the opportunity to interact with scientists in order to learn more about research. In regard to this latter statement, the author firmly believes that the scientific community has a responsibility to educate the public about SCI research and at the same time take the opportunity to learn from the people living with SCI about what is truly important to improving the quality of life. By doing so, basic scientists may develop outcome measures that are more relevant to the priorities of the consumers.

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TABLE 1. SURVEY QUESTIONNAIRE

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1. What level is your spinal cord injury and what year did it occur?
 2. What gain of function would dramatically improve your life?
Rank the following functional recovery in order of importance to you, 1 being most important and 7 being least important:
 - A) arm/hand function
 - B) upper body/trunk strength and balance
 - C) bladder/bowel function, elimination of Dysreflexia
 - D) sexual function
 - E) elimination of chronic pain
 - F) normal sensation
 - G) walking movement
 3. Do you think exercise rehabilitation is an important aspect of regaining function?
 4. Do you currently have access to any exercise rehabilitation? Describe.
 5. Name:
Address:
Phone:
Email:
Age:
 6. Any further comments or suggestions.
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The questionnaire was distributed via email, postal mail, the internet, and word of mouth throughout the SCI community. The categories of functional recovery were designed to be broad and inclusive, rather than narrow and exclusive.

The seven categories were chosen based on consumer feedback, empirical evidence, and categories predominantly used in the literature (Estores, 2003; Cohen and Marino, 2000; Widerstrom-Noga et al., 1999). The study was approved by the University of California Irvine Institutional Review Board and all guidelines regarding human subjects were followed. Attached to the survey was an introductory statement explaining the purpose of the survey, directions for participating, the right to privacy, what the results were to be used for, and that the scientist conducting the survey also had a spinal cord injury. This information served as the informed consent statement, as required by the Institutional Review Board.

Participant Recruitment

Dissemination of the survey was performed by creating links with various disability websites, support groups, and magazines via the Internet and postal mail (including *360mag*, National Center on Physical Activity and Disability, National Spinal Cord Injury Association, New Mobility, Paralysis Resource Center, Paralyzed Veterans of America, *Paraplegia News*, Spinal Injuries Association, United People With Disabilities, When You Need Group Support) and by word of mouth throughout the SCI community (e.g., email, personal interview). Any individual with an injury that was defined to a specific level

of the spinal cord was included in the study with the exception of minors, prisoners, and adults with cognitive impairments or who were medically incapacitated/likely to need "surrogate" consent. Individuals were given the option of participating anonymously. Both complete and incomplete injuries were included. This was done because participants were unlikely to know the true completeness of their injury, especially those individuals diagnosed prior to the time when the American Spinal Injury Association (ASIA) classification scale was developed (Ditunno, 1992), refined (Maynard et al., 1997), and widely implemented.

RESULTS

Demographics

There were a total of 774 respondents, of which 93 were unusable, for a final number of 681 participants. The unusable respondents returned the survey either without providing a specific injury level or ranked the categories in a non-consecutive manner. Of the usable participants, 51% were quadriplegic and 49% were paraplegic. In addition, 25% were female, 65% male, and 10% chose to participate anonymously with regard to sex.

Importance of Arm/Hand Function to Quadriplegic Quality of Life

To most appropriately assess the priorities of the SCI population, the responses were grouped into quadriplegics and paraplegics. For quadriplegics, as shown in Figure 1A, 48.7% of the participants indicated that regaining arm and hand function would most improve their quality of life and another 11.5% ranked increased upper body/trunk strength and balance as most important. Thirteen percent ranked sexual function to be the priority while 8.9% regarded bladder/bowel function and the elimination of autonomic dysreflexia to be more important. The latter is a life-threatening condition defined by a sudden and severe increase in blood pressure and simultaneous decrease in heart rate induced by a noxious stimulus below the level of injury; individuals with a T6 injury or above are at risk of developing autonomic dysreflexia. Regaining walking movement was the highest priority to only 7.8%, followed by regaining normal sensation (6.1%), and eliminating chronic pain (4%).

Importance of Sexual Function to Paraplegic Quality of Life

For the paraplegic participants, 26.7% ranked regaining sexual function to be the most important to quality of life (Fig. 1B). This was followed by improving bladder/bowel function and eliminating autonomic dysreflexia (18%) and increasing upper body/trunk strength and balance (16.5%). Regaining walking movement was ranked higher by paraplegics (15.9%) than by quadriplegics (see above), as was eliminating chronic pain (12%). Regaining normal sensation (7.5%) and improving arm/hand function (3.3%) were regarded as the least important to improving the quality of life of paraplegics.

Both Quadriplegics and Paraplegics Share Similar Priorities When Ranking Bladder/Bowel and Sexual Function as the First or Second Most Important Factor Affecting Quality of Life

Similar priorities were chosen by quadriplegics and paraplegics when the first and second ranked functions were combined. To perform this analysis, the number of people (quadriplegics and paraplegics were analyzed separately) who ranked a particular function as the first priority were combined with the number of people who ranked that same function as the second priority. Because of the differences in the most important recovered function indicated by quadriplegics versus paraplegics

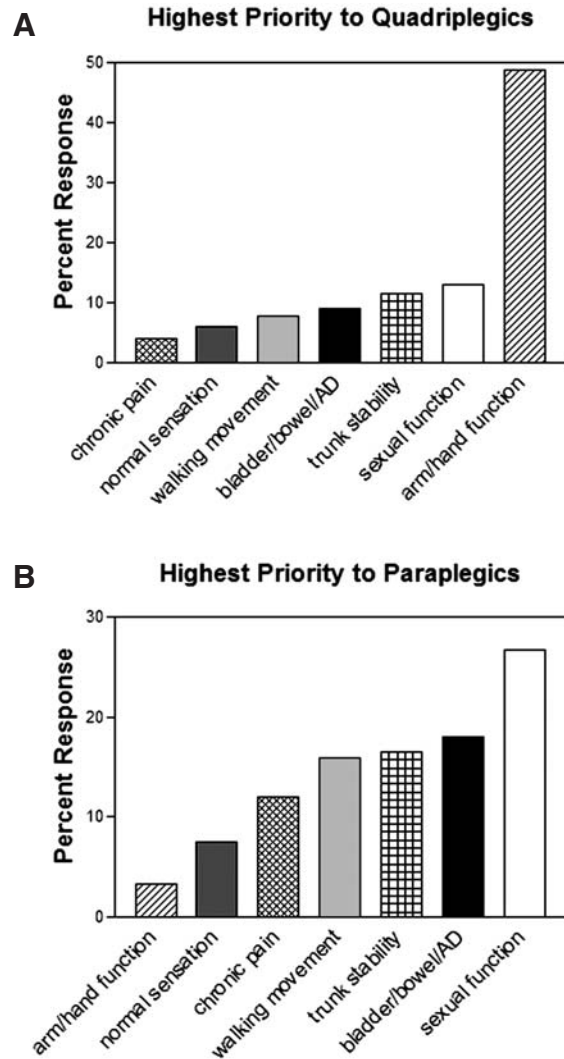


FIG. 1. A representation of the areas of functional recovery ranked as the highest priority to quadriplegics (A) and paraplegics (B). Percent response is the percentage of individuals ranking that function as being most important to improving their quality of life.

(arm/hand function versus sexual function), this analysis was performed in order to assess functions that were important to both groups. Regaining bladder/bowel function and eliminating autonomic dysreflexia was the first or second highest priority for 39.7% of quadriplegics and 38% of paraplegics (Fig. 2). Similarly, regaining sexual function was the first or second highest priority to 28.3% of quadriplegics and 45.5% of paraplegics. Regaining walking movement, however, was ranked differently between the two groups, with 14.2% of quadriplegics and 38.1% of paraplegics ranking it as the first or second most important function to improve quality of life.

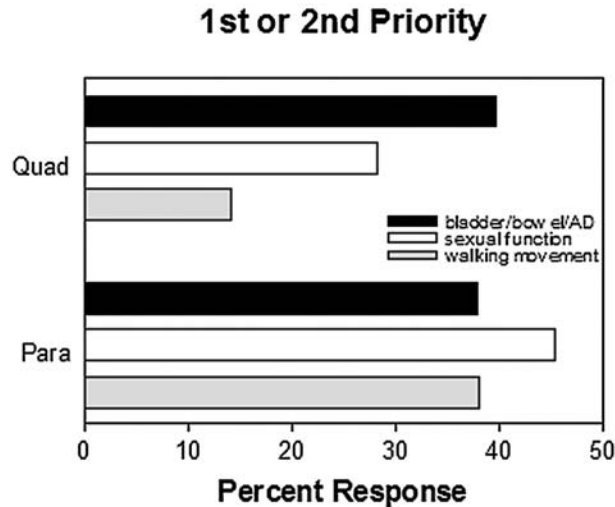


FIG. 2. Shared priorities of quadriplegics and paraplegics. The percentage of individuals that ranked regaining bladder/bowel function as the first or second most important function to improving quality of life were combined. The same was done for those individuals ranking sexual function or walking movement as the first or second most important function.

Of the total population, regaining some level of bladder/bowel function, sexual function, elimination of pain, or normal sensation was the highest priority to 47.8% combined. For the paraplegic population specifically, this was 64.3%.

Slight Priority Differences Based on Gender

To explore the possibility that females and males may have different priorities regarding recovered function, the data were separated into the following four groups based on the 616 participants who provided gender identification: female quadriplegics ($n = 79$), female paraplegics ($n = 92$), male quadriplegics ($n = 242$), and male paraplegics ($n = 203$). The function most important to improving the quality of life was determined for each group. As demonstrated in Figure 3, female and male quadriplegics shared very similar priorities, with regaining arm/hand function still being the most important, 53.2% and 48.3%, respectively. One slight difference was that recovering upper body strength and trunk stability was more important to female quadriplegics (13.9%) than male quadriplegics (9.5%). Female and male paraplegics also shared similar priorities, but with a few interesting differences. Regaining sexual function remained the highest priority to paraplegics, but was slightly more important to females (30.4%) than males (23.1%). Conversely, recovering normal sensation was a bit more im-

portant to male paraplegics (7.4%) than females (3.3%). The most striking difference, however, was that walking movement was more important to male paraplegics (18.7%) than to female paraplegics (9.8%), male quadriplegics (8.7%), or female quadriplegics (5.1%). One must take into consideration, however, with respect to the gender differences presented here, that the sample size for males was roughly three times greater than that for females.

Does the Importance of Recovering Different Functions Change with Time Post-Injury?

In order to assess whether or not priorities changed with increased time post-injury, a simple longitudinal analysis was performed. Of the 681 participants, 630 provided the year they were injured. These 630 were separated into two groups, those injured between 2000 and 2003 (“0–3 years post-injury”; 76 quadriplegics and 78 paraplegics) and those injured prior to 2000 (“>3 years post-injury”; 248 quadriplegics and 228 paraplegics). The separation into groups with these time frames is similar to groupings used in another study (Livneh and Martz, 2003). Figure 4A shows the highest priorities for quadriplegics in both of these groups. Regaining arm and hand function was the highest priority regardless of time post-injury. Regaining walking movement was slightly more

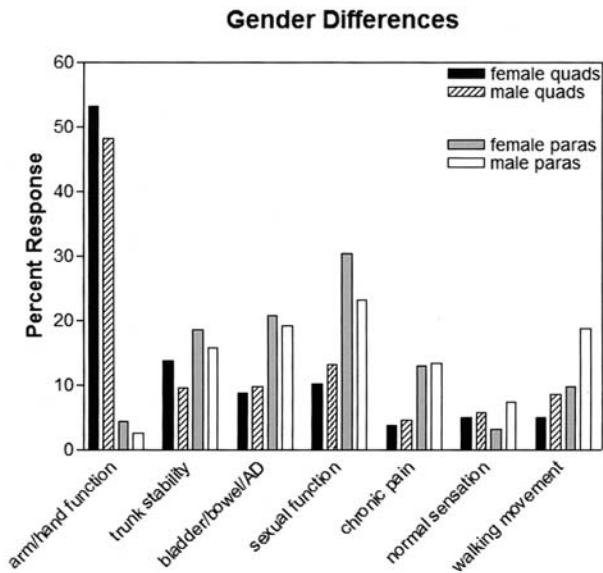


FIG. 3. Slight differences based on gender. Participants who provided gender identification (616 of 681) were separated into four groups: female quadriplegics (79), female paraplegics (92), male quadriplegics (242), and male paraplegics (203). The functions ranked as highest priority to improving quality of life for each of the groups are represented as percent response.

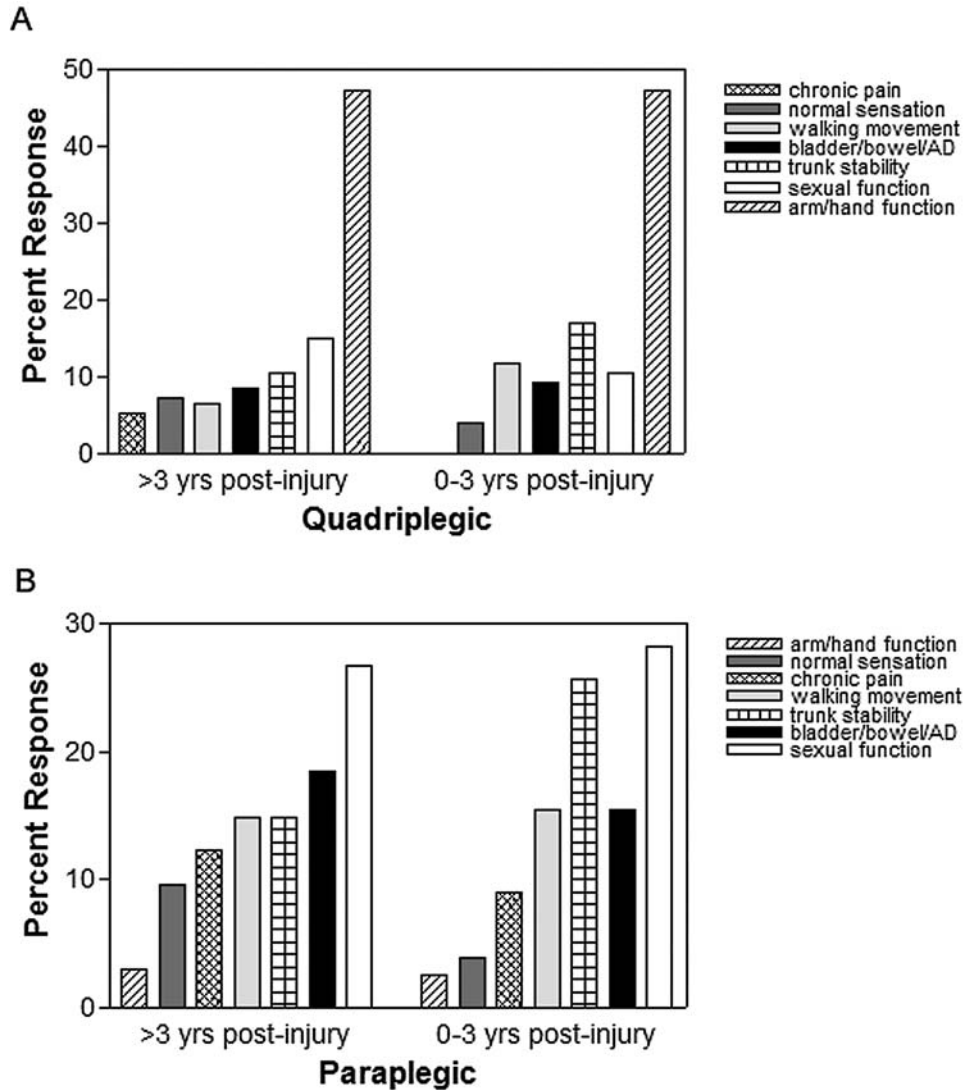


FIG. 4. Longitudinal analysis. Participants who provided their year of injury (630 of the 681) were broken up into two groups: those injured between 2000 and 2003 were designated as 0–3 years post-injury, and those injured prior to 2000 were designated as >3 years post-injury. The functions ranked as highest priority to improving quality of life for each of the groups are represented for quadriplegics (A) and paraplegics (B).

important to individuals injured <3 years (11.8%) compared to those injured for longer than 3 years (6.5%). Eliminating chronic pain was not a priority to quads injured <3 years (0%), but became increasingly important to improving quality of life after 3 years (5.2%).

Figure 4B demonstrates that regaining sexual function was most important to the quality of life of paraplegics regardless of the time post-injury. Regaining walking movement was not significantly influenced by time after injury. Importantly, however, eliminating chronic pain and regaining normal sensation were ranked much higher by individuals injured longer than 3 years (12.3% and

9.6%, respectively) compared to those injured shorter than 3 years (9% and 3.8%, respectively). Improving upper body/trunk strength and balance was more important to the quality of life of those injured <3 years (25.6%) than those injured more than 3 years (14.9%).

Access to Exercise Rehabilitation

The final topic assessed was to determine if individuals with SCI think exercise rehabilitation is important to functional recovery and, if so, whether or not they have access to such exercise. As shown in Table 2, 96.5% of all the

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TABLE 2. ACCESS TO EXERCISE REHABILITATION

<i>Is exercise important to functional recovery?</i>		<i>Currently have access to exercise?</i>		<i>With or without a trained therapist?</i>	
No	3.5%	—		—	
Yes	96.5%	Unknown	24.2%	—	
		No	18.9%	—	
		Yes	56.9%	With	12.2%
				Without	44.7%

The percentage of individuals stating that exercise was important to functional recovery was further broken down into those who did or did not have access to exercise and whether that exercise was overseen by a trained therapist. This information was taken from detailed descriptions provided by the participants.

participants indicate that they consider exercise to be an important aspect of functional recovery. Of this 96.5%, 18.9% did not currently have access to exercise, 56.9% did have access, and 24.2% did not indicate either way. To further analyze the basic type of exercise described by those individuals that had access to exercise, the description provided by each individual was retrospectively categorized as either exercising on their own, typically at home, or being overseen by a trained therapist (physical therapist), typically in an outpatient setting. Of the 56.9% that did have access to exercise, only 12.2% had access to a trained therapist. The remaining 44.7% exercised on their own, with a variety of exercise equipment. Thus, a total of at least 63.6% (44.7% exercising on their own plus 18.9% without any access to exercise) did not have access to a trained therapist to oversee their exercise regiment.

DISCUSSION

The data from this survey demonstrate the preferences of the spinal cord injured community in terms of the importance of regaining partial functional recovery to the quality of life. The return of arm and hand function was by far the highest priority to quadriplegics. For paraplegics, the most desired improvement was sexual function. Regaining bladder and bowel function and eliminating autonomic dysreflexia was of similar importance to both injury populations when analyzed as a combination of the first and second priorities. Finally, the overwhelming majority of all participants regarded exercise as an important aspect of functional recovery, yet more than half of these individuals did not have access to a trained therapist to guide proper exercise.

Unintentional Exclusion or Selection Bias

The National Spinal Cord Injury Database (2001) reports the percentage of quadriplegics at 51.6 and para-

plegics at 46.3 (with this information being unavailable for 1.4% and the remaining 0.7% experiencing recovery prior to discharge). A similar distribution was reflected in the present survey, with 51% quadriplegics and 49% paraplegics. With regard to gender, the nationally reported 4 to 1 ratio of male to female was similarly represented here (25% female and 65% male), although 10% chose to remain anonymous. Thus, despite the fact that participant recruitment was not randomized, the demographics of the current study reflect the statistics reported for SCI in the United States. In addition, the high number of participants (681) is sufficient to result in meaningful data.

One caveat of the dissemination method was that the number of individuals who looked at the survey on the web and decided not to participate could not be determined. However, two things were observed during the study that led to increased participation. First, not only was the short and simple nature of the survey design relevant, but having direct access to it on the internet removed the requirement/barrier of having to respond via mail, telephone, or in person, all of which are more difficult for a spinal cord injured individual. In support of the use of the internet, a study by Edwards et al. (2002) demonstrated that individuals with SCI were interested in receiving information about research and that the internet was the most preferable method by which to gain access to such information, as opposed to receiving newsletters or attending seminars. Second, the fact that the author is a scientist with a spinal cord injury proved to be an important quality when individuals chose to participate, based on the existence of a common bond.

There is the possibility that the wording and dissemination methods of the survey may have resulted in unintentional exclusion or selection bias. One category unintentionally left off the survey was respiratory capacity. However, only 70 of the 347 quadriplegic participants had an injury between C1–C4. It may be that this popu-

lation was hard to gain access to via the dissemination methods used because of their extremely limited mobility and independence. It is clearly recognized and acknowledged by the author, however, that improvements in respiration and the elimination of ventilator-dependence are extremely important to the quality of life, and this topic should be at the forefront of research.

Finally, the population over 40 years of age may not use email or the internet as widely as the population under 40. This could have resulted in selection bias. However, 297 of the participants responded via postal mail, personal interview, or telephone interview. The remaining 384 individuals participated via the survey website. Thus, the distribution was approximately 50% from the internet and 50% from non-internet sources.

Relevance of the Areas of Functional Recovery Surveyed to Basic Science

Not surprisingly, regaining arm and hand function was the most desired function for quadriplegics. This is consistent with the fact that recovering even partial arm and hand function can have an enormous impact on independence. This finding is similar to previous studies demonstrating that increased independence enhances the quality of life of individuals with SCI (Francischini et al., 2003; Wuolle et al., 2003; Waters et al., 1996; Mulcahey et al., 1994). This need highlights the importance of including cervical injury models and to implement multiple, sensitive forearm and forepaw behavioral tests in these animal models. These injury models and behavioral tests should be modeled in a manner that will be translationally relevant to humans so that future treatments to be tested clinically can draw as much information as possible from the basic science field. To aid the development of translationally relevant models and outcome measures, basic science departments are encouraged to foster dialogue with clinical departments having expertise with human SCI, in addition to promoting interactions with people in the community living with SCI.

Although the concentration on thoracic injury models has been justified by their greater practical simplicity, this does not outweigh the significance of understanding more about the normal responses to cervical injury and the possibilities for therapeutic intervention in this very different situation. For example, the study of neuroprotection after acute SCI could lead to greater levels of detectable, quantifiable functional sparing in cervical injuries compared to thoracic. Regarding chronic SCI, sprouting or regeneration across a short distance may result in functional recovery that is more easily detected and more clinically beneficial when using cervical injury models. Thus, although cervical injury models can be

more complicated and risky, we, as basic scientists, have a responsibility to address these difficulties if we are to attempt to meet the needs of our consumers.

The majority of paraplegic participants regarded sexual function to be most important to improving the quality of life. Sexual issues affecting men with SCI particularly focus on dysfunctions regarding erection and ejaculation (Hubscher and Johnson, 2000, 1999; Biering-Sorensen and Sonksen, 2001). Impaired sexual arousal and orgasm are problems for women with SCI (Jackson and Wadley, 1999; Sipski et al., 1997, 1995a, 1995b; Sipski and Alexander, 1993). In addition, the possibility of bladder and bowel accidents stimulated by sexual intercourse is an area of great concern to women (White et al., 1993), yet little research can be found addressing this issue. The development of autonomic dysreflexia during genital stimulation is a risk faced by both men and women, especially for men using penile vibrostimulation to induce ejaculation (Howards et al., 2002; Brackett et al., 1998; Sansone et al., 1997). Clearly, sexual function is adversely impacted by SCI and expanded research in the entirety of this area, not just limited to fertility purposes, can lead to treatments that profoundly improve the quality of life of affected individuals. Sexual dysfunction may be difficult to address in animal models and it may be that new models need to be developed. This is an excellent example wherein interactions between clinicians, basic scientists, and individuals with SCI (each sharing their own expertise) could lead to the development of translationally relevant research. As the majority of individuals with SCI become injured during early adulthood, and as advances in medicine continue to increase the lifespan of those individuals, it is imperative that this subject not be dismissed or merely considered a luxury for those individuals living with paralysis.

The importance of recovering bladder and bowel function is a shared priority to quadriplegics and paraplegics. Until recently, renal failure was the leading cause of death for people with SCI (National SCI Database, 2001). Despite medical advances in urologic management, bladder and bowel dysfunctions continue to adversely impact daily life (Benevento and Sipski, 2002). Most individuals have one of three options for bladder management (indwelling catheter, external catheter [for men], or intermittent catheterization), each with its own advantages and disadvantages. Autonomic dysreflexia, which can be triggered by distension of both the bladder and bowel, is a life-threatening situation for individuals with spinal injury at T6 or above (Karlsson, 1999). In addition, constant spasticity of the bladder wall can induce persistent, mild dysreflexia symptoms, which are very disruptive to daily functioning unless medicated, often with an anticholinergic drug (Burns et al., 2001). The problems as-

sociated with neurogenic bowel can severely influence the quality of life on a daily basis (Kirk et al., 1997; Stiens et al., 1997). It can take months to years for a person with SCI to develop a reliable, effective bowel routine. The amount of time required to perform a bowel movement can vary from person to person and even from day to day within the same person. Having bowel accidents is not only physically uncomfortable, but also socially humiliating. For those individuals whose injury severity requires another person to conduct their bowel management, there are multiple physical, psychological, and social humiliations to be endured. These issues, in addition to the impairments in sexual function described above, warrant intensive investigation into the underlying mechanisms of autonomic dysfunctions after SCI and the imperative need for developing treatments for those dysfunctions. Anything that can be done to increase function and independence regarding bladder and bowel function will be a great advance in medical science.

Interestingly, eliminating chronic pain was not a priority to quads injured <3 years (0%), but becomes increasingly important to improving quality of life after 3 years (5.2%). A similar trend was evident for paraplegics (9% of those injured <3 years and 12.3% of those injured >3 years). In addition, chronic pain was of higher concern to paraplegics than quadriplegics in this study, both females and males. For individuals who experience chronic pain, this can be the most devastating complication of SCI (Widerstrom-Noga and Turk, 2003; Eaton, 2003; Hulsebosch, 2002; Burchiel and Hsu, 2001; Siddall and Loeser, 2001). Recent evidence suggests that there may be a relationship between chronic pain and autonomic dysreflexia in persons with chronic cervical SCI (Widerstrom-Noga et al., 2004). There are multiple types of drugs used to treat chronic pain, but none are completely effective in eliminating the problem (Burchiel and Hsu, 2001). The onset and evolution of chronic pain after SCI is not yet fully understood and requires continued, extensive study in both the laboratory and clinical settings.

Another aspect that must be addressed in the laboratory and clinical setting is longterm exercise for chronic SCI. There are some studies demonstrating the benefits of longterm exercise in humans with SCI (Ditor et al., 2003; Hicks et al., 2003; Nash et al., 2002; Jacobs et al., 2002, 2001). Recent studies in animal models have shown exercise to have a positive effect on outcome after SCI (Van Meeteren et al., 2003; Lankhorst et al., 2001; Dupont-Versteegden et al., 2000, 1998). Clearly, exercise is likely to be beneficial to the outcome of SCI. However, the results of the current study indicate that only 12.2% of the participants who had access to long-term exercise were supervised by a trained therapist. Aside

from the already known benefits of exercise to overall health, the lack of access to exercise and therapists to guide this exercise will be a problem if clinical treatments are developed for chronic SCI which require the reversal of muscle atrophy, for example, in order for benefits of the treatment to be detectable.

One area of research that warrants discussion is that of functional electrical stimulation (FES), for here many advances have been made in regard to restoring functional independence and, as technology increases, the potential for improving the quality of life of many individuals with SCI will also increase. Most notably, FES has been used for many years to reduce muscle atrophy and induce standing and walking ability (Postans et al., 2004; Agarwal et al., 2003a; Jacobs and Mahoney, 2002; Mirbagheri et al., 2002; Field-Fote, 2001; Brissot et al., 2000; Ladouceur and Barbeau, 2000; Wieler et al., 1999; Klose et al., 1997; Moynahan et al., 1996) and consumers have been satisfied with the outcomes (Agarwal et al., 2003b; Brown-Triolo et al., 2002; Kilgore et al., 2001). There are many other applications, however. FES has been used extensively to restore bladder and bowel control (Vastenholt et al., 2003; Creasey et al., 2001a; Egon, 1998; Brindley, 1994; Van Kerrebroeck et al., 1993; Brindley et al., 1982) and has been shown to reduce the long-term economic consequences of bladder and bowel management (Creasey et al., 2001b). Though the performance of a posterior sacral rhizotomy is an important drawback to consider, and a source of controversy, future advances may lead to the use of FES as a more widespread option for people with SCI to consider. In addition, research is being conducted on the use of FES for improving tissue health and preventing pressure ulcers (Bogie and Triolo, 2003), an extremely important complication of SCI not addressed in this study. Work is also currently being performed on the use of FES to improve functioning of the diaphragm to decrease the dependence on ventilators for those individuals with high cervical injuries. Of extreme relevance, however, are past, current, and future studies involving the use of FES to improve arm and hand function for quadriplegics (Peckham et al., 2002, 2001; Bryden et al., 2000; Grill and Peckham, 1998; Keith et al., 1989). Limited arm function for quadriplegics requires dependence on personal care attendants for daily functions. Increasing arm function, of any amount, will decrease the reliance on attendant care, increase independence, and substantially improve quality of life.

Perspectives

The mismatch of desired outcomes with outcomes usually targeted by researchers is a concern to the SCI pop-

ulation. Thus, those who use animal models should be encouraged to adapt those models and collect data on more translationally relevant outcome measures, such as those highlighted above. Though many of these issues will be quite difficult and challenging to unravel, the value of the research that is done will depend on its relevance to these problems that strongly impact quality of life.

What constitutes quality of life? That is a very subjective question because people value different things. After a spinal cord injury, many things are lost and the complexity of the loss can be better understood by a person who has sustained a paralyzing injury. Being paralyzed is so much more than not being able to walk. Physiologically, there are severe impairments in bladder, bowel, cardiac, respiratory, sensory, and sexual function (Blight, 2002). Socially, relationships are difficult to maintain, and reintegration into society is quite challenging (Noreau and Fougere, 2000; Richards et al., 1999; Whiteneck et al., 1999). Financially, initial and long-term medical costs are extremely burdening and, unfortunately, large proportions of people living with paralysis are not able to return to full-time work and, thus, are dependent upon state and federal assistance (Yasuda et al., 2002; National SCI Database, 2001). Psychologically, the loss of a “normal” life can be devastating for months or years depending upon the person, and this can result in further physiological, social, and financial problems (Stiens et al., 2002; Krause et al., 2000). All of these issues factor in definitions of the quality of life. Many research tools have been developed to try to measure quality of life after SCI (Manns and Chad, 2001; Hallin et al., 2000), and the validity of these tools is improving with repeated use.

Basic scientists are not typically trained to address the psychological, social, and economic issues resulting from SCI, but there remains a responsibility to be aware of these problems because of the impact on physiological dysfunctions and quality of life. Restoring any amount of physiologic function will lead to an equivalent increase in independence, and this will have a profoundly positive effect on the adverse psychological, social, and economic factors associated with the SCI population. One must keep in mind, however, the complexity that every spinal cord injury is different and every person is different. Thus, what may be important to one person may be less of a concern for another person even if they have a similar degree of injury. Further, what may be important to a person at one point in their life may have a different value at a later point in time. The ultimate goal of disease-oriented research, however, is to apply our results to the human condition and with that comes a host of complications. One factor necessary in the successful attainment of that goal is to draw upon the intimate knowledge of the people living with the disease and to

target functional recovery. These data present an important roadmap for discovery (Zerhouni, 2003) with regard to spinal cord injury.

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