

Matthew Kehn, B.A.<sup>1</sup>; Thilo Kroll, Ph.D.<sup>2</sup>

<sup>1</sup>National Rehabilitation Hospital, Washington, DC; <sup>2</sup>University of Dundee, Scotland

## Background:

- ♦ Mortality rates for people with SCI are declining; life expectancy continues to increase (Strauss et al 2006); focus shifts to rehabilitation, self-management and prevention of secondary conditions
- ♦ People with SCI are more susceptible to secondary and chronic conditions like osteoporosis, cardiovascular disease, diabetes and arthritis (Groah 2002; DeVino 1999; Karlsson 1999; Bauman 2000)
- ♦ Physical activity and exercise among this population can help prevent secondary conditions (Jacobs & Nash 2001) and increase functionality, quality of life and social integration (Duran 2001; Noreau 1993; Manns 1999)
- ♦ As a group, people with SCI are less likely to be physically active and are rarely targeted for health promotion

## Objective:

To understand what deters, motivates and facilitates exercise among people with a spinal cord injury (SCI)

## Methods:

### Sample:

26 adults with SCI (15 "exercisers", 11 "non-exercisers") randomly recruited from a pool of 592 survey participants for in-depth phone interviews

### Defining "Exercise":

The survey instrument used in our survey study, from which these participants were randomly selected, allowed participants to self define "exercise". Those reporting no exercise were identified as "non-exercisers".

### Semi-structured Interview:

Phone interviews, recorded with permission, were 20–30 minutes & focused on:

- ♦ Experiences with exercise before injury
- ♦ Experiences with exercise since injury
- ♦ Logistics of current exercise regimen
- ♦ Barriers and facilitators of exercise
- ♦ Perceived benefits of exercise
- ♦ Perceived impact of exercise on secondary conditions
- ♦ Experiences with pain management
- ♦ Future plans for exercise

### Analysis:

- ♦ Bi-variate, non-parametric analysis for demographic differences; Mann-Whitney U tests for continuous data &  $\chi^2$  tests for independent samples for categorical data; Fisher Exact Test when cells sizes were < 5
- ♦ Transcripts of interviews analyzed by two analysts independently; initial thematic categories recorded, coded, discussed and refined

## Results:

### Participant characteristics:

Variable	"Exercisers" N=15 Median (min, max)	"Non-exercisers" N=11 Median (min, max)	P
Age	52 (23, 74)	46 (34, 54)	.171
Sex			.228
Female	4 (26.7%)	6 (54.5%)	
Male	11 (73.3%)	5 (45.5%)	
Ethnicity			.238
Caucasian/White	12 (80%)	11 (100%)	
Non-Caucasian	3 (20%)	0	
Education			.999
= 12 years	3 (20%)	3 (27.3%)	
> 12 years	12 (80%)	8 (72.7%)	
Income			.456
< \$20	4 (27%)	3 (27%)	
\$20k - \$60k	3 (20%)	5 (46%)	
\$61k - \$100k	7 (46%)	1 (9%)	
> \$100k	0	1 (9%)	
Working			.781
Full/Part-time	6 (40%)	5 (45%)	
Not working	9 (60%)	6 (55%)	
Marital status			.462
Married/cohabitating	9 (60%)	5 (45%)	
Single/Living alone	6 (40%)	6 (55%)	
Duration (Years)	6 (1, 32)	20.5(6, 32)	.029
Injury Level			.462
C-level	9 (60%)	5 (45.5%)	.999
T-level	5 (33.3%)	4 (36.4%)	.206
Completeness of injury			
Complete	5 (33.3%)	6 (55%)	
Incomplete	10 (66.7%)	3 (27%)	

- ♦ Significant difference only in "duration of injury"

### What participants said about their experiences with exercise:

- ♦ Most participants, regardless of exercise group, were physically active prior to injury.
- ♦ Many indicated that it took time after injury to adjust expectations and adapt to new exercise regimens.
- ♦ The rehabilitative process was cited for helping participants identify feasible exercise routines that matched their post-injury lifestyle.

"I got hurt in 1999 and I didn't start working out until the summer of 2004. At first I was in therapy and at that time I was working part time and going to school part to full time and it was just a really hard struggle. Around that time it just wasn't in my mind. I didn't think about it much." ~ Exerciser, male, 35, T7 incomplete

- ♦ The majority of "exercisers" completed their routines at home, compared to a gym.
- ♦ Stretching and muscle strengthening were the most frequently reported activities; aerobic activities were more problematic to perform (particularly for tetraplegics).
- ♦ Physical activities included both daily activities, such as gardening and mopping the floor, as well as formalized activities, such as isometrics, cycling, swimming, weight lifting and range of motion.
- ♦ Participants used a range of equipment, including customized bi- and tricycles, stretch bands, braces, free weights, gym-based machines, treadmills and glide standers.
- ♦ Although some noted their independence when exercising, most respondents required at least some assistance from professionals or family members to transfer to equipment or for stretching.

"I have a personal care assistant and he spends six hours a day with me and part of that of course is bathing and so forth, but four hours of that is exercising. I'm a tetraplegic. I can walk a little distance. We do balance exercises, work my arms and hands. And at night, in my garage I have a hand cycle, and I use it." ~ Exerciser, male, 70, C3 incomplete

### What participants said about barriers to exercise:

- ♦ The most common barrier cited was a "limited return on investment"; it was perceived by several that the amount of time and energy required to reach the perceived beneficial level of activity was too demanding or unrealistic.

"Yeah, it's just too much work for too little benefit. I've tried to do a few things here and there but, it just takes too much time and too much effort and I don't think the benefits out way the costs" ~ Non-exerciser, male, 57, injury level unknown

"I find it, the exercise that I do, to be so different from the exercise I did before my injury in so many ways that it's also kind of psychologically difficult to exercise. It doesn't feel good... at all... I don't get sweaty... I don't get my heart rate up... I can feel my legs but not that well. So, it either makes me spasm or it like... or it just... wears me out." ~ Exerciser, male, 35, C4 incomplete

- ♦ Some felt frustrated and disinterested in the activities that they were capable of doing, particularly modified sports.

"I couldn't do what I used to do. And there were a few things that I tried to do after the accident that were so discouraging that I quit. The main thing there was that I tried to play tennis in a wheelchair and I hated it. It wasn't the same game. I let it go because I couldn't stand facing it that way. I got on a horse eleven months after the accident, still in a wheelchair, and it felt so good, since I had been on horses since I was four. And I think, I was reserving judgment because I didn't want to be disappointed the way I was with tennis." ~ Exerciser, female, 63, C5 incomplete

- ♦ Those interested in being active cited accessibility as a barrier; lack of accessible facilities and traveling far to reach facilities.
- ♦ Lack of personal assistance was a barrier as well as costs associated with purchasing home equipment.

"I could probably get on a cycle machine that is motorized to move my legs, but... I guess the main obstacle is having someone else take up their time to help me do it. I would need at least one or two people." ~ Non-exerciser, male, 50, C4

- ♦ As with the general population, a busy lifestyle and lack of motivation were cited for inactivity.
- ♦ A lack of knowledge about how and where to exercise was cited; particularly for those in a rural environment.

"I have always been trying to find a really good exercise routine with light weights for someone in a chair. They come out with exercise videos but they don't have the balance issues that people in chairs have to deal with. The bulkiness of the wheelchair, those kinds of things... and so I've never seen that. For me, that would be awesome. Just to have some kind of exercise video with suggested cardio and strengthening activities. I can't find it, whether it's out there, I don't know." ~ Non-exerciser, female, 45, T7 complete

- ♦ Fear of physical damage was also cited.

"The other reason I don't walk more than I do is because I get nervous that with my abnormal gate I might wear out my joints also. I often wonder if because of the abnormal way I'm moving I'm putting abnormal stress on my joints. I think that if I were to go faster or longer I might get into trouble a little bit. I don't even know if I should be thinking about that, but I am." ~ Exerciser, male, 35, C4 incomplete

- ♦ Issues with insurance, particularly Medicare and Medicaid, were noted as a barrier, including a lengthy bureaucratic process and limited coverage.

"If I have neck pain they [Medicare] might give me a week or two of therapy but that's all. And I believe I would have been a lot further ahead as far as mobility if I were allowed to have more therapy." ~ Exerciser, female, 66, T7 incomplete

### What participants said about facilitators to exercise:

- ♦ Both "exercisers" and "non-exercisers" identified "motivation" as the most critical facilitator to being active.
- ♦ "Exercisers" listed health concerns as an impetus, particularly weight management and the avoidance of secondary conditions.

"Mostly just to keep up my strength and also being in my chair I put on quite a bit of weight and as a 24 year old girl that kind of bothers me." ~ Exerciser, female, 24, C6 complete

- ♦ Stress management and general good feelings were mentioned.
- ♦ Desire to be independent and a reduction in personal assistance.
- ♦ Accessibility was a facilitator for those who were active.
- ♦ Medication, mostly to control pain, was also offered.
- ♦ Some "non-exercisers" saw "social support" as a possible facilitator for being active.

"I think I would probably need to be in something more structured where I would have to go and do it with someone else. To really get myself to do it at this age..." ~ Non-exerciser, female, 44, C5 incomplete

### What participants perceived as a benefit of exercise:

- ♦ Non-exercisers mostly perceived benefits in terms of general health and well being; exercisers specified broad benefits that they attributed directly to the activities they were undertaking.

"...at home also I mop the floor. Well I don't mop them, I bucket mop them. And I do that because I have to move my legs and I try to get my legs exercise. And I know I'm getting it because I get some feeling... and I can feel the muscles move..." ~ Exerciser, male, 54, T12 incomplete

- ♦ Weight management; cardiovascular and respiratory fitness; improved motor control; maintenance of physical strength
- ♦ Prevention of secondary conditions, particularly pressure ulcers, UTIs, bowel obstruction, bone loss and muscular atrophy

"You know, I think it has a lot to do with the bowel and bladder. When I don't exercise, I become congested and I'm just out of it... so I think all of that [exercise] helps me to be well all around, but most of all with my bladder and bowel changes." ~ Exerciser, male, 54, T12 incomplete

- ♦ Reduction in depressed mood; management of stress; control of pain; personal discipline and structure; better quality of life

## Conclusion:

Most people with SCI are principally motivated to engage in exercise to maintain their health and prevent secondary conditions. Pre-injury exercise levels are not good predictors of post-injury activity. A better understanding of pre-injury experiences and the removal of socio-environmental barriers to exercise, such as access to affordable venues, personal assistance and knowledge is essential to increasing the number of exercise active people after SCI. Understanding, and incorporating, the experiences of people in the community can help tailor exercise and health promotion programs aimed at teaching newly injured patients to successfully pursue healthy living and self-management. Clinicians and therapists play a vital role at addressing early on any obstructive thinking by their patients.

\*This project is funded by NIDRR grant #H133B03114