

# Disparities in subjective well-being, participation, and health after spinal cord injury: A 6-year longitudinal study

James S. Krause<sup>a,\*</sup>, Lisa K. Saladin<sup>a</sup> and Rodney H. Adkins<sup>b</sup>

<sup>a</sup>College of Health Professions, Medical University of South Carolina, Charleston, SC, USA

<sup>b</sup>Los Amigos Research and Education Institute, Inc., Rancho Los Amigos National Rehabilitation Center, Downey, CA, USA

**Abstract.** *Objective:* To identify disparities and changes in subjective well-being, participation, and health over a 6-year period as a function of race-ethnicity and gender in persons with spinal cord injury (SCI).

*Methods:* Stratified sampling was used to maximize inclusion of women and racial-ethnic minorities. Three model SCI systems participated, representing the Southeastern, Western, and Mountain regions of the United States. 250 participants completed measures on two occasions. Similar portions of Caucasians ( $n = 62$ ), African-Americans ( $n = 61$ ), American-Indians ( $n = 56$ ), and Hispanics ( $n = 71$ ) participated. Women made up approximately 43.1% of the sample. Three sets of outcome measures assessed: (a) subjective well-being and depressive symptoms, (b) participation, and (c) health.

*Results:* MANOVA indicated significant effects for race-ethnicity (between subjects effect) and time (within subjects effect) but not for gender or the interaction effects. A Bonferroni correction was used to compare outcomes as a function of race-ethnicity and time. Five outcomes were significantly related to race-ethnicity, whereas no items were significantly related to the time effect after the Bonferroni correction. Caucasians reported best subjective well-being scores in several domains followed by African-Americans. Caucasians also reported more hours out of bed than either African-Americans or Hispanics.

*Conclusion:* Over a 6-year period, race-ethnicity continued to be related to differences in subjective well-being and participation but not health. Disparities in outcomes did not systematically increase or diminish over time, suggesting that once developed, such disparities are unlikely to change in the absence of intervention.

Keywords: Spinal cord injury, disparities, depression; health, quality of life

## 1. Introduction

### 1.1. Background and significance

Traumatic spinal cord injury (SCI) generally causes permanent sensory and motor loss that adversely affects function and may significantly affect quality of life. Recent estimates indicate that the annual incidence of SCI

in the United States is about 40 cases per million [5,8, 12,16] and that there are approximately 250,000 Americans living with the sequelae of a SCI [18]. Since the majority of SCI occur in individuals who do not have private health insurance (54%), the long term economic impact of these injuries may be devastating [18]. It is estimated that the life time direct costs associated with a SCI at age 25 causing paraplegia is \$977,142, and life time direct costs associated with a SCI causing quadriplegia at age 25 is \$1.6–2.9 million depending on the level of injury [18].

While it is clear that the majority of individuals with SCI are Caucasian (63%) [18], a significant number of other racial-ethnic groups experience SCI. Yet, outside

---

\* Address for correspondence: James S. Krause, PhD, Department of Rehabilitation Sciences, College of Health Professions, Medical University of South Carolina, 77 President St, Suite 117, PO Box 250700, Charleston, SC 29425, USA. Tel.: +1 843 792 1337; Fax: +1 843 792 5649; E-mail: krause@muscd.edu.

of analyses of the National SCI Database, racial-ethnic groups other than Caucasians continue to be underrepresented in SCI research. This is most likely due to convenience sampling where enrollment is based on the most available participants. With the recent focus on racial and ethnic disparities in health care, increased emphasis needs to be placed on collecting SCI data from racial-ethnic populations in order to investigate potential racial disparities especially as they pertain to outcomes.

The portion of Caucasians in the National Spinal Cord Injury Statistical Center Database has decreased since 2000, although, because the contributing hospitals change, it is unknown whether the changes in distribution reflect a different pattern of etiology as a function of race-ethnicity, or simply changes in the designated systems who contribute data. Population data from the state of South Carolina (Authors) indeed suggests that the incidence of SCI has decreased among Caucasians but not significantly changed among African-Americans. Population data is required in epidemiologic studies as literally all cases of SCI in a given region are identified with no selective bias based on admission to a particular hospital.

A recent report by the Institute of Medicine, "Unequal Treatment; Confronting Racial and Ethnic Disparities in Health Care," reviewed and summarized the literature pertaining to disparities in health care and documented the existence of significant health disparities with variations in both access and outcome as a function of race-ethnicity [23]. For example, non-Caucasian patients are less likely to receive cardiac bypass surgery [1,9,20], hemodialysis and kidney transplant [4], appropriate diagnostic tests for cancer [17], appropriate cardiac medications [10], and analgesic medications after bone fractures [24], and they are more likely to receive a lower quality of clinical services [1]. However, there are many gaps in the existing health disparities research, including the lack of data from special populations such as SCI. While investigations of underrepresented groups with SCI have increased and include a greater focus on aging and gender issues, studies of diverse racial-ethnic groups are rare. Furthermore, existing studies have focused primarily on African-American participants with relatively few studies using either Hispanic or American-Indian samples.

The studies that have been conducted thus far examining disparities post-SCI have focused on racial and gender differences in quality of life (QOL) which Fuhrer [6] divided into two critical components; par-

ticipation and subjective well-being (SWB). Participation refers to the extent to which an individual is actively engaged in community/home activities or how he or she spends time. Conversely, SWB measures the subjective perception of how satisfied one is with these activities.

The few published studies that have examined race and/or gender disparities post-SCI have documented disparities in one or both components of QOL. For example, African-Americans have reported significantly lower self-concept in relation to social-self, moral-ethical self, self-satisfaction, and behavior [3]. Similarly, African-American participants, particularly women, were found to be at a substantially higher risk for depressive symptomatology [15]. In contrast, Fuhrer and associates [7] found no differences in risk of depression as a function of race-ethnicity but did report that women with SCI were significantly more at risk for serious depression than were men. Factors that were found to be associated with increased risk of depression included lower socioeconomic status [15] and decreased mobility [7]. Additional research has demonstrated that racial and gender differences in SWB are more likely to emerge when subjects are questioned regarding specific subjective outcomes than when general subjective outcomes are measured. For example, Krause found that African-American participants reported lower scores when rating their SWB in the specific areas of finances and careers but similar scores on the general measures of life engagement and negative affect [13].

In a more comprehensive analysis, SWB, participation, and self-reported health varied as a function of gender and race-ethnicity (Caucasian, African-American, American-Indian, and Hispanic) [14]. Significant differences related to race and ethnicity were found in 6 of the 7 SWB scales from the Life Situation Questionnaire-revised version [14]. Consistent with previous research, Caucasians reported the best SWB outcomes with the most consistent differences in the areas of career opportunities and finances. Also of interest was the significantly higher score for interpersonal relations for African-Americans compared to other racial-ethnic groups and the significantly lower scores reported by American-Indians compared to any other group. Significant racial-ethnic differences were identified on indicators of participation, with Caucasians and American-Indians reporting the highest scores on the Craig Handicap Assessment and Reporting Technique (CHART). Significant racial-ethnic differences were also observed for self-rated overall health and satisfaction with overall health, as Caucasian participants

rated their own health significantly higher than Hispanic participants.

More limited gender differences in SWB post-SCI were also identified in the study [14]. Previous reports of higher depression rates for women were confirmed with women reporting higher depression scores compared to men in all non-Caucasian racial-ethnic groups except American-Indians where the opposite was observed. Women reported higher scores for interpersonal relations and lower scores for living circumstances compared to men. In addition, women reported a greater number of poor mental health days and lower satisfaction with health. There were no gender differences in participation.

### 1.2. Summary of research

Despite the fact that one of the primary goals of Healthy People 2010 is the elimination of health disparities [19], there has been a lack of systematic investigation of SCI outcomes as a function of race-ethnicity and gender. Most studies that expanded their focus to more diverse racial-ethnic groups have focused solely on African-American participants [14]. Most clearly absent are investigations comparing outcomes among multiple racial-ethnic groups simultaneously. In addition, longitudinal research is particularly needed to identify how these outcomes evolve and change over time.

### 1.3. Purpose

The purpose of this study was to identify the stability of several QOL and health outcomes over a 6-year period as a function of gender and race-ethnicity among participants with SCI. This is a direct follow-up to the multi-site study comparing outcomes between Caucasians, African-Americans, Hispanics, and American-Indians [14]. Comparing multiple outcomes *over time* among multiple racial-ethnic groups in a single study represents a significant enhancement over previous research and will determine the extent to which disparities change over time.

### 1.4. Hypotheses

1. Significant racial-ethnic differences will again be observed with Caucasians reporting the best overall outcomes.
2. Gender differences will be observed for depressive symptomatology, with women reporting a greater number of symptoms.

3. Longitudinal comparisons will reveal increasing disparities over time as a function of race-ethnicity.

## 2. Methods

### 2.1. Participants

All participants were interviewed at one of three collaborating model SCI centers from different regions of the United States including the Southeastern, Western, and Mountain regions. All participants were adults and had traumatic SCI of at least one year duration at the time of enrollment, six years prior to the follow-up. A stratified sampling procedure was used to oversample groups generally underrepresented in SCI research. The primary criterion was race-ethnicity, followed by gender. Therefore, given the overall limited number of available cases, we first maximized selection by oversampling diverse racial-ethnic groups. If a sufficient pool of prospective participants was available within a particular racial-ethnic group, we oversampled women in order to include relatively equal portions of men and women. The sampling strategy was successful in producing a nearly equal distribution of Caucasians, African-Americans, Hispanics, and American-Indians. There were a total of 475 cases from the three centers during the initial assessment prior to initiation of the follow-up data collection.

Six years later, of the 475 participants at baseline, 250 participated in the follow-up (52.7%). There is no data available on causes of attrition. Table 1 summarizes the participant characteristics at follow-up as a function of race-ethnicity. There was a nearly equal distribution of participants as a function of race-ethnicity, as the percentage ranged from a low of 22.4% for American-Indians to a high of 28.4% for Hispanics (Caucasian, 24.8%; African-American 24.4%). Overall, 43.1% were women, which is substantially higher than the 18% observed in the total SCI population. This included a relatively equal number of African-American, Caucasian, and Hispanic women ( $n = 33$ , 32, and 29 respectively). There were substantially fewer American-Indian women ( $n = 14$ ). Fifty-three percent of the total sample reported cervical level injuries, with complete injuries making up 35.7% of the total injuries. The average age at the time of the follow-up was 48.5 years, and the average number of years since SCI onset was 20.0. Participants averaged 12.7 years of education.

Table 1  
Participant characteristics by gender and race and ethnicity

	Caucasian		African-American		American-Indian		Hispanic	
	Male	Female	Male	Female	Male	Female	Male	Female
N of cases	30	32	28	33	42	14	42	29
Age	53.6	51.2	50.9	51.8	43.5	47.1	45.1	47.4
Years since injury onset	20.0	20.8	20.0	22.2	16.9	21.1	19.3	21.5
Cause of injury	%	%	%	%	%	%	%	%
Motor vehicle	40.0	53.1	50	46.9	85.4	92.9	28.6	48.3
Sporting	10.0	12.5	7.1	3.1	2.4	0	2.4	3.4
Fall/flying object	40.0	21.9	3.6	12.5	4.9	0	9.5	3.4
Violence	3.3	6.3	35.7	37.5	4.9	7.1	57.1	34.5
Other	6.7	6.3	3.6	0	2.4	0	2.4	10.3
Level of injury								
Cervical Injury	60.0	56.3	60.7	54.8	45.2	50.0	56.1	50.0
Neurologic completeness								
No sensation/movement below injury	30.0	34.4	42.9	21.2	40.5	21.4	50.0	27.6
Some sensation, no movement below injury	26.7	21.9	25.0	30.3	31.0	42.9	26.2	31.0
Some movement below injury, cannot walk	26.7	25.0	17.9	33.5	14.3	21.4	14.3	10.3
Movement and can walk	16.7	15.6	10.7	12.1	14.3	14.3	7.1	31.0
Years of education completed	13.5	14.2	14.1	12.0	12.2	12.9	11.3	11.9

## 2.2. Procedures

After obtaining approval from the Institutional Review Board, each participating center re-contacted participants six years later and asked them to complete follow-up materials by interview. Prior to the time of the interview itself, copies of the interviews were sent to participants. A data collector subsequently contacted the participant to complete the informed consent and to perform the interview. On occasion, participants returned the interview via mail. They were offered \$50 remuneration to participate in the study. All completed materials were sent to the lead center for data processing and analysis.

## 2.3. Instruments

The study included measures of SWB (the Life Situation Questionnaire-Revised, Older Adult Health and Mood Questionnaire), participation (Craig Handicap Assessment and Reporting Technique), and health outcomes (the Behavioral Risk Factor Surveillance System).

### 2.3.1. Life Situation Questionnaire – revised version (LSQ-R)

The LSQ-R was used to measure 8 aspects of SWB, including 7 scales which were derived from factor analysis of two major sets of subjective items [2,13]. These included 20 satisfaction items and 30 problems items, each of which used 5-point rating scales. Satisfaction items required the participant to rate his/her satisfaction with a particular area of life on a 5-point scale. The

problems items required participants to rate the degree to which different areas of their lives have caused them problems (1 = no problem; 5 = major problem). In addition, two items required participants to rate their overall adjustment to their SCI on a 10-point scale, once rating their current adjustment and a second time predicting their adjustment in five years (these were combined into a single scale).

The 7 homogeneous scales developed from factor analysis of the satisfaction and problems items [13], included: (a) Engagement, (b) Negative Affect, (c) Health Problems, (d) Finances, (e) Career Opportunities, (f) Living Circumstances, and (g) Interpersonal Relations. Higher scores indicate more favorable SWB for five of the seven scales (all except Negative Affect and Health Problems, where lower scores are more favorable). These scales have been converted to T-scores with a mean of 50 and standard deviation of 10 in order to allow direct comparisons across scales and to compare samples with those obtained when developing the LSQ-R. Alpha coefficients for the factor scales ranged from 0.79 to 0.92, with an average of 0.86.

### 2.3.2. Older Adult Health and Mood Questionnaire (OAHMQ)

The OAHMQ is a 22-item measure developed to measure depressive symptoms in older adults and among people with physical disabilities or other health conditions [11]. There are few items that reflect physical or vegetative symptomatology, as these types of symptoms may parallel the actual sensory and motor complications associated with SCI. There are three diagnostic categories with the OAHMQ: (a) non-

depressed (0–5 points), (b) clinically significant symptomatology (6–10 points), and (c) probable major depression (11–22 points). It was validated against clinical assessments by psychiatrists and psychologists and was found to have highly acceptable internal (0.87) and test-retest reliability (0.84). Validity ranged from 0.80 for sensitivity to 0.87 for specificity.

### 2.3.3. The Craig Handicap Assessment and Reporting Technique (CHART)

The CHART is a measure of 5 domains of participation: (a) Physical Independence, (b) Mobility, (c) Occupation, (d) Social Integration, and (e) Economic Self-sufficiency [26]. It was designed to provide a measure of the degree to which disability limits participation. Three selected items were taken from the CHART each of which reflects a marker of participation, including: (a) daily hours out of bed, (b) times leaving home per week, and (c) the number of nights spent away from home during the previous year (excluding time spent in the hospital).

### 2.3.4. Behavioral Risk Factor Surveillance System (BRFSS)

The BRFSS is a standardized instrument that is used by the Centers for Disease Control to monitor relevant basic health behaviors within the general population and in specific regions of the country [21]. Items selected from the BRFSS for this study included: (a) general health, (b) health change in the past year, (c) poor physical health days in the past month, and (d) poor mental health days in the past month.

## 2.4. Data analysis

Current participants and non-participants from the 6-year follow-up (time 2) were compared on biographic, injury-related, educational, and outcome measures from the preliminary assessment (time 1) in order to identify the degree of selective attrition during follow-up. T-tests and the chi square statistic were used for the biographic, injury, and educational variables. The multivariate analysis of variance (MANOVA) was used to determine significance of differences in outcomes measures at time 1 between responders and non-responders.

In the primary analyses, repeated measures MANOVA with Wilks' Lambda was used to identify overall differences for the within factor of time of measurement (i.e., changes between time 1 and time 2), the two between subjects main effects (gender, race-ethnicity), and the interaction effects. Wilks' Lambda

is the pooled ratio of error variances to effect variance plus error variance ( $R^2 = 1 - \lambda$ ). The three primary effects of interest were the main effect for time (within subjects effect), which would indicate an overall change in outcomes over the six-year period, and the two interaction effects (time and gender; time and race-ethnicity). These latter interaction effects would indicate unequal amounts of change over time as a function of gender or race-ethnicity (i.e., changes in *disparities* over time). Follow-up univariate analyses of variance (ANOVA) were performed with Tukey-B post-hoc tests to identify which groups differ in any event of a significant main or interaction effect. A Bonferroni correction was used to adjust the alpha level on follow-up ANOVAs (0.05/# of follow-up univariate ANOVA). Items that were significant prior to the Bonferroni correction were considered non-significant trends. Effect sizes are reported for all follow-up ANOVA.

## 3. Results

### 3.1. Respondents and non-respondents

Analysis of the data revealed only two significant differences between those who were maintained in the study at time 2 (responders) and those unavailable for further testing at time 2 (non-responders). The non-responders had a longer mean time post-injury (13.4 years versus 11.8 years;  $p < 0.05$ ) and had a higher incidence of non-cervical injuries (55.9% versus 46.8%;  $p < 0.05$ ) compared to the responders. There were no significant differences between the two groups for age, gender, race, cause of injury, completeness of injury, current employment, education completed or the MANOVA across the outcomes measures taken at time 1.

### 3.2. Primary analysis

The results of the MANOVA (reported in Table 2) indicated a significant main effect for race-ethnicity,  $F(48, 396) = 1.58, p < 0.01$  and a significant within subjects effect for time,  $F(16, 133) = 1.92, p < 0.05$  (Table 2). Wilks' lambda for race-ethnicity was 0.593 ( $R^2 = 0.407$ ) and 0.812 for the time effect ( $R^2 = 0.188$ ). The main effect for gender and the interaction effects were all *non-significant*. Therefore, univariate tests with post-hoc contrasts were used to identify the nature of the differences as a function of race-ethnicity and time. There were a total of 32 follow-up ANOVAs,

Table 2

Multivariate analysis of variance as a function of gender, race-ethnicity, and time

	Value*	F	DF	Sig
Between subjects effects				
Gender	0.943	0.51	16,133	0.941
Race	0.593	1.58	48,396	0.010
Race by Gender	0.693	1.09	48,396	0.331
Within subjects effects				
Time	0.812	1.92	16,133	0.024
Time by Race	0.774	0.74	48,396	0.899
Time by Gender	0.993	0.60	16,133	0.883
Time by Gender by Race	0.765	0.78	48,396	0.855

\*Wilks Lambda: The formula  $(1 - \text{value})$  is equivalent to variance explained or effect size.

so the Bonferroni correction was  $p < 0.0015 (0.05/32)$ .

Of the SWB scales, 4 were significantly related to race-ethnicity (Tables 3 and 4). These included: engagement, career development, interpersonal relations, and the adjustment scale. Post-hoc comparisons revealed that Caucasians and African-Americans reported significantly higher engagement scores than either Hispanics or American-Indians. Caucasians also reported significantly higher career development scores than either Hispanics or American-Indians. African-Americans reported significantly higher career development scores than Hispanics. In terms of interpersonal relations, both Caucasians and African-Americans reported higher scores than Hispanics. American-Indians reported significantly lower adjustment scores than each of the other groups. Non-significant trends (significant at  $p < 0.05$  prior to the Bonferroni correction) were observed for 4 additional variables, including: negative affect, finances, living circumstances, and depressive symptoms. There was also a non-significant trend for the time effect on the adjustment variable.

Significant differences emerged as a function of race-ethnicity on one of the three CHART items: hours out of bed,  $F(3,227) = 6.23, p < 0.001$ . Caucasians reported significantly more hours out of bed per day (13.6) than either African-American (11.5) or Hispanic participants (11.3). There was a non-significant time effect,  $F(1,227) = 5.51, p < 0.05$ .

None of the effects were significant for health.

#### 4. Discussion

The current study was designed to identify disparities in SWB, participation, and health outcomes among diverse participants including those typically underrepresented in SCI research (i.e., women and racial-ethnic

Table 3

Univariate analysis of variance for each outcome as a function of time and race-ethnicity

Variable	Race F	Time F	Contrasts
Psychological			
Engagement	<b>5.33*</b>	1.30	<b>1,2&gt;3,4</b>
Negative Affect	3.33 <sup>§</sup>	0.50	3>1
Health Problems	0.21	0.04	None
Finances	2.98 <sup>§</sup>	1.31	1>3
Career Development	<b>10.49*</b>	3.32	<b>1&gt;3 1,2&gt;4</b>
Living Circumstances	3.29 <sup>§</sup>	2.59	1>4
Interpersonal Relations	<b>5.58*</b>	1.31	<b>1,2&gt;4</b>
Oahmq	2.61 <sup>§</sup>	0.72	3>1
Adjustment	<b>6.78*</b>	6.18 <sup>§</sup>	<b>1,2,4&gt;3</b>
Chart			
Hours out of bed per day	<b>6.23*</b>	5.51 <sup>§</sup>	<b>1&gt;2,4</b>
Days out of the house per week	2.22	0.53	None
Nights away from home per year	1.77	3.08	None
Health			
General Health	2.02	2.16	None
Health Change in Past Year	2.81	2.11	None
Days in Poor Physical Health	0.48	1.10	None
Days in Poor Mental Health	1.108	2.19	None

\* $p < 0.001$ , <sup>§</sup> = non-significant trend;

1 = Caucasian; 2 = African-American; 3 = American-Indian; 4 = Hispanic.

groups) and the extent to which observed disparities increase over time. This study was a follow-up to earlier comparative data on gender and racial-ethnic differences [14].

##### 4.1. Support for hypotheses

The first hypothesis was partially supported. There were significant racial-ethnic differences in outcomes favoring Caucasians. However, the majority of the differences were in the area of SWB (three significant effects after correction for multiple statistical tests) and one indicator of participation (hours spent out of bed per day), with no differences in health outcomes. With the exception of hours out of bed, African-Americans were not significantly different than Caucasians on any of the other outcomes. They reported significantly better outcomes than either Hispanics or American-Indians on selected variables. However, American-Indians and Hispanics had lower scores than Caucasians and/or African-Americans in all three areas of SWB where significant racial-ethnic differences were demonstrated. In addition, American-Indians had the lowest adjustment scores compared to all other groups. The racial-ethnic disparities noted in SWB were generally consistent with the findings from the study examining outcomes from these participants 6 years earlier [14] indicating that many of the racial-ethnic disparities in

Table 4  
Means and standard deviations for each outcome as a function of race-ethnicity and time of measurement

Variable	Caucasian		African-American		American Indian, Alaskan Native		Hispanic		Time 1	Time 2
	Time 1	Time 2	Time 1	Time 2	Time 1	Time 2	Time 1	Time 2		
SWB										
Engagement	52.8 (9.2)	51.8 (9.2)	53.7 (9.4)	50.7 (10.9)	49.6 (9.8)	47.6 (9.6)	47.5 (9.4)	49.5 (10.4)	50.8 (9.7)	49.9 (10.1)
Negative affect	47.3 (7.8)	49.3 (8.8)	47.7 (9.2)	50.2 (11.7)	51.8 (10.0)	52.3 (10.0)	52.0 (10.8)	49.4 (19.5)	49.7 (9.7)	50.2 (10.1)
Health problems	49.2 (10.2)	50.3 (10.1)	50.6 (9.8)	50.9 (11.5)	50.4 (8.7)	50.8 (9.6)	51.3 (10.2)	48.9 (9.0)	50.4 (9.8)	50.2 (10.0)
Finances	49.6 (10.4)	53.4 (10.6)	49.0 (10.9)	47.9 (10.5)	49.8 (10.3)	48.8 (9.3)	46.9 (7.9)	49.2 (8.5)	48.7 (9.9)	49.8 (9.9)
Career Development	50.8 (10.1)	54.9 (9.2)	50.6 (9.9)	49.4 (19.3)	48.0 (10.2)	48.1 (10.1)	44.2 (8.4)	47.3 (9.0)	48.3 (10.0)	49.9 (9.8)
Living Circumstances	53.0 (7.5)	52.2 (9.1)	52.5 (8.9)	49.1 (10.8)	50.3 (9.1)	49.4 (9.5)	48.6 (9.7)	48.7 (10.5)	51.0 (9.0)	49.8 (10.1)
Interpersonal Relations	53.6 (8.4)	51.6 (8.6)	54.7 (9.9)	52.0 (9.0)	50.0 (9.7)	49.3 (11.0)	48.2 (9.7)	49.3 (10.7)	51.6 (9.7)	50.5 (9.9)
OA/HMQ	4.1 (4.0)	3.8 (4.3)	5.3 (5.4)	5.1 (4.9)	6.1 (5.6)	6.5 (5.8)	5.9 (5.6)	4.9 (5.6)	5.4 (5.2)	5.1 (5.2)
Adjustment	17.4 (2.9)	16.8 (3.3)	17.6 (3.5)	16.0 (4.2)	14.6 (4.4)	14.7 (4.0)	16.6 (3.7)	16.0 (3.8)	16.6 (3.8)	15.9 (3.9)
Health										
Overall health	3.3 (0.9)	3.3 (0.9)	3.1 (1.0)	3.1 (1.0)	3.2 (1.1)	3.1 (0.8)	3.0 (1.0)	2.9 (0.9)	3.1 (1.0)	3.1 (0.9)
Days in poor health	5.8 (7.4)	4.5 (7.0)	4.8 (8.4)	5.9 (9.5)	4.5 (7.3)	7.4 (9.8)	5.0 (8.2)	5.2 (7.0)	5.0 (7.8)	5.7 (8.3)
Days in poor mental health	4.1 (6.5)	3.3 (6.4)	4.9 (8.5)	6.0 (9.9)	3.1 (4.5)	6.5 (9.7)	3.2 (5.0)	3.9 (6.7)	3.8 (4.5)	4.8 (8.3)
Health change in past year	3.2 (0.8)	3.1 (0.7)	3.3 (0.8)	3.2 (0.9)	3.5 (0.9)	3.4 (0.8)	3.1 (0.9)	3.1 (0.9)	3.3 (0.8)	3.2 (0.8)
participation										
Hours out of bed per day	13.9 (2.8)	13.4 (3.4)	11.8 (3.9)	11.3 (4.1)	12.4 (3.7)	11.8 (4.2)	11.3 (3.8)	11.2 (3.7)	12.3 (3.7)	11.9 (3.9)
Days out of the house per week	4.6 (2.3)	4.7 (2.2)	3.6 (2.5)	3.7 (2.4)	3.8 (2.4)	3.8 (2.5)	4.1 (1.8)	4.3 (2.2)	4.0 (2.2)	4.2 (2.3)
Nights away from home per year	15.0 (19.8)	12.3 (18.7)	11.1 (28.0)	5.05 (8.5)	15.9 (26.7)	12.7 (26.4)	11.3 (27.4)	7.68 (19.6)	13.3 (25.6)	9.4 (19.5)

SCI outcomes have persisted over time. However, it is important to note that the racial-ethnic difference in ratings of overall health noted in the earlier study were no longer significant. This may be due to the fact that there was substantially less power at time 2 due to smaller sample sizes. The overall effect size or  $R^2$  for race-ethnicity was just over 40%.

The presence of disparities in SWB in the absence of broader disparities in participation and health suggests that SWB may be more closely associated with socioeconomic status than perceived health and that there are additional racial-ethnic differences that require further examination. One of the three significant findings was for career development. Furthermore, the lower engagement and interpersonal relations scores reported by Hispanics and American-Indians may be related to their lower scores on career development (consistent across both measurement times). In addition, health care systems variables such as language barriers or geographic availability and patient level variables such as cultural differences in expectations, compliance, and acceptance of treatment that were not collected in this study may contribute to the observed racial-ethnic disparities in outcomes [23].

There was no support for the second hypothesis of gender differences in outcomes. This is somewhat surprising given that the preliminary study had identified gender differences in selected areas, including depressive symptoms [14]. However, the magnitude of differences in the previous research was not great. The absence of significant gender differences, both as a main effect or interaction effect with time, is encouraging as it suggests an absence of disparities in outcomes between men and women across diverse racial-ethnic groups.

Lastly, the third hypothesis was not supported. After the statistical correction for multiple tests of significance, there was no tendency for disparities to increase selectively over time as a function of either race-ethnicity or gender. This suggests that disparities are likely to occur early after SCI onset and remain present over extended periods of time but not necessarily increase over time.

#### 4.2. Implications

Results from this study are consistent with the existing literature documenting racial-ethnic disparities in both access to health care and subsequent health care outcomes. In a review using three national databases, Weinick and colleagues [25] documented that health

disparities increased from 1977 to 1996 particularly among Hispanics and that 50–75% of disparities would remain if income and insurance coverage were eliminated. Access to resources may be a critical factor in successful adaptation. According to the National Spinal Cord Injury Statistical Center [18], only 20.7% of patients have reported receiving outpatient psychological and/or vocational counseling within the first year post-injury. While additional patients may have received counseling at a later date, these data appear to indicate a need for more resources to be allocated for psychological and vocational counseling targeted at diverse racial-ethnic populations.

#### 4.3. Limitations

There were four primary limitations of the current study. First, because of our use of diverse racial-ethnic groups and the prevalence of SCI among these groups, our study is somewhat limited in power. This is an inherent problem in doing investigations with underserved populations. They are underrepresented in research because they are underserved, and this makes it very difficult to identify sufficient cases. It is also difficult to identify samples with comparable characteristics. Therefore, study findings must be considered conservative tests of real differences. We have not attempted to interpret non-significant trends, even though it would be possible to make the case for no statistical correction given the unusual nature of the data. However, the readers may choose to draw their own inferences from these findings.

Second, because within subjects effects require change over time, they are generally more difficult to demonstrate outside of intervention studies that are specifically designed to bring about such changes. Nevertheless, even subtle changes over time may have important clinical significance. Once again, we believe that we had a conservative test of the effect of the time variable.

Third, although this study presented data for four different racial-ethnic groups, we were unable to obtain a sufficient number of Asian-Americans for comparative analyses. Also, race-ethnicity was confounded with geographic region (i.e., African-Americans from the Southeastern regions; American-Indians from the Mountain regions; and Hispanics from the Western regions of the United States). This trend is also seen in the general population.

Fourth, because of the collaborative nature of the project, we were unable to differentiate causes of non-



response such as refusal, geographic mobility, and mortality. However, our analyses of selective attrition identified only two factors that were related to selective attrition (years post-injury and injury level), neither of which were outcomes but which may have biased the results. Gender and race-ethnicity, the primary variables of interest in the current study, were not significantly related to attrition.

Lastly, although we made extensive effort to capture a sufficient number of women within each of the four racial-ethnic groups, we were limited in our ability to identify a sufficient number of American-Indian women.

#### 4.4. Future research

This study lays a solid foundation for understanding basic differences in general outcomes as a function of race-ethnicity, yet, clearly more research needs to be conducted. Future research would benefit from evaluation of specific environmental and cultural factors that may help to *explain* the pattern of similarities and differences in outcomes observed in the current study. Further research is needed to examine the factors contributing to these disparities and to determine effective interventions for eliminating these disparities. Evaluation of more specific secondary conditions, rather than just general health outcomes, would be beneficial. The ultimate challenge is to develop and evaluate interventions to reduce disparities in outcomes.

#### Acknowledgements

This research was supported by field initiated grants from the National Institute for Disability and Rehabilitation Research of the Office of Special Education and Rehabilitation Services (#H133G020218, #H133G050165) and the Model Spinal Cord Injury Systems Grant #H133N000005. The opinions here are those of the grantee and do not necessarily reflect those of granting agencies.

#### References

- [1] J.Z. Ayanian, J.S. Weissman, S. Chasan-Taber and A.M. Epstein, Quality of care by race and gender for congestive heart failure and pneumonia, *Med Care* **37** (1999), 1260–1269.
- [2] N.M. Crewe and J.S. Krause, An eleven-year follow-up of adjustment to spinal cord injury, *Rehabilitation Psychology* **35** (1991), 205–210.
- [3] M. Davis, B. Matthews, W.T. Jackson, E. Fraser and J.S. Richards, Self-concept as an outcome of spinal cord injury: The relation to race, hardiness, and locus of control, *SCI Psychosocial Process* **8** (1995), 90–101.
- [4] A.M. Epstein, J.Z. Ayanian, J.H. Keogh, S.J. Noonan, N. Armistead, P.D. Cleary, et al., Racial disparities in access to renal transplantation, *New England Journal of Medicine* **343** (2000), 1537–1544.
- [5] P.R. Fine, M.J. DeVivo and A.B. McEachran, Incidence of acute traumatic hospitalized spinal cord injury in the United States, 1970–1977, *Am J Epidemiol* **115** (1982), 475–479.
- [6] M.J. Fuhrer, The subjective well being of people with spinal cord injury: Relationships to impairment, disability and handicap, *Topics in SCI Rehabilitation* **1** (1996), 56–71.
- [7] M.J. Fuhrer, D.H. Rintala, K.A. Hart, R. Clearman and M.E. Young, Depressive symptomatology in persons with spinal cord injury who reside in the community, *Archives of Physical Medicine & Rehabilitation* **74** (1993), 255–260.
- [8] B.K. Go, M.J. DeVivo and J.S. Richards, The epidemiology of spinal cord injury, in: *Spinal Cord Injury: Clinical Outcomes from the Model Systems*, S.L. Stover, J.A. DeLisa and G.G. Whiteneck, eds, Aspen, Gaithersburg, MD, 1995, pp. 21–55.
- [9] E.L. Hannan, M. Van Ryn, J. Burke, D. Stone, D. Kumar, D. Arani et al., Access to coronary artery bypass surgery by race/ethnicity and gender among patients who are appropriate for surgery, *Med Care* **37** (1999), 68–77.
- [10] H. Herholz, D.C. Goff, D.J. Ramsey, F.A. Chan, C. Oritz, D.R. Labarthe et al., Women and Mexican Americans receive fewer cardiovascular drugs following myocardial infarction than men and non-Hispanic-Whites: The Corpus Christi Heart Project, 1988–1990, *Journal of Clinical Epidemiology* **49** (1996), 279–287.
- [11] B.J. Kemp and B.M. Adams, The Older Adult Health and Mood Questionnaire: A measure of geriatric depressive disorder, *Journal of Geriatric Psychiatry and Neurology* **8** (1995), 162–167.
- [12] J.F. Kraus, C.E. Franti, R.S. Riggins, D. Richards and N.O. Borhani, Incidence of traumatic spinal cord lesions, *Journal of Chronic Disease* **28** (1975), 471–492.
- [13] J.S. Krause, Dimensions of subjective well-being after spinal cord injury: an empirical analysis by gender and race/ethnicity, *Arch Phys Med Rehabil* **79** (1998), 900–909.
- [14] J.S. Krause and L.E. Broderick, Outcomes after spinal cord injury: Comparisons as a function of gender and race ethnicity, *Arch Phys Med Rehabil* **85** (2004), 355–362.
- [15] J.S. Krause, B.J. Kemp and J.L. Coker, Depression after spinal cord injury: Relationship with gender, race/ethnicity, aging and socioeconomic indicators, *Arch Phys Med Rehabil* **81** (2000), 1099–1109.
- [16] W.O. McKinley, A.B. Jackson, D.D. Cardenas and M.J. DeVivo, Long-term medical complication after traumatic spinal cord injury: A regional model systems analysis, *Arch Phys Med Rehabil* **80** (1999), 1402–1410.
- [17] L.F. McMahan, R.A. Wolfe, S. Huang, P. Tedeschi, W. Manning and M.J. Edlund, Racial and gender variation in use of diagnostic colonic procedures in the Michigan Medicare population, *Med Care* **37** (1999), 712–717.
- [18] National Spinal Cord Injury Statistic Center (NSCISC), Fact Sheet, Birmingham, University of Alabama, 2006. <http://www.spinalcord.uab.edu/show.asp?durki=21446>.
- [19] U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, Healthy People 2010, Rockville, MD, 2005.

- [20] L.A. Petersen, S.M. Wright, E.D. Petersen and E.D. Daley, Impact of race on cardiac care and outcomes in veterans with acute myocardial infarction, *Med Care* **40** (2002), 186–196.
- [21] E. Powell-Griner, J.E. Anderson and W. Murphy, State-and sex-specific prevalence of selected characteristics—behavioral risk factor surveillance system, 1994 and 1995, *Morbidity and Mortality Weekly Report CDC Surveill Summ* **46** (1997), 1–31.
- [22] A.W. Selassie, E.E. Pickelsimer, L.A. Lineberry, J. Nicholas and L. Veldheer, Epidemiology of traumatic spinal cord injury in South Carolina – 1981–2003, *Journal of the South Carolina Medical Association*, in press.
- [23] B. Smedley, A. Stith and A. Nelson, eds, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, National Academy Press, Washington, DC, 2002.
- [24] K.H. Todd, N. Samaroo and J.R. Hoffman, Ethnicity as a risk factor for inadequate emergency department analgesia, *Journal of the American Medical Association* **269** (1993), 1537–1539.
- [25] R.M. Weinick, S.H. Zuvekas and J.W. Cohen, Racial and ethnic differences in access to and use of health care services 1977–1996, *Med Care Res Rev* **57** (2000), 36–54.
- [26] G.G. Whiteneck, S.W. Charlifue, K.A. Gerhart, J.D. Overholser and G.N. Richardson, Quantifying handicap: a new measure of long-term rehabilitation outcomes, *Arch Phys Med Rehabil* **73** (1992), 519–526.

Copyright of NeuroRehabilitation is the property of IOS Press and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.