Satisfaction with Life after Spinal Cord Injury: A look over 35 years

Stephanie Kolakowsky-Hayner, PhD
Kimberly Bellon
Jerry Wright, MS
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Stephanie Kolakowsky-Hayner, PhD, Kimberly Bellon, and Jerry Wright, MS have no financial interest to disclose.
Learning Objectives

Objectives for this 45 minute presentation include:

1). To describe previous research on the functional and psychosocial contributors to SWL following a SCI.

2). To describe the multivariate predictors of SWL at different time periods following SCI.

3). To summarize qualitative survey from individuals with SCI regarding what has most positively and negatively impacted their SWL following their injury.

4). To discuss commonly used outcome measures related to life satisfaction after SCI and present the advantages and disadvantages of each.
Obtaining CME/CE Credit

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Life Satisfaction after SCI

• Diminished life satisfaction after SCI has been well established in the literature.

• Factors involved await fuller characterization.

• Persons with SCI tend to report lower subjective well-being than individuals without significant disability.


Impacts of SCI

• Physical ability to care for oneself and home
• Access the community
• Ability to work
• Family dynamics
• Interpersonal relationships

• Individuals with SCI often score lower on measures of physical, mental and social health

Predictors of Low Satisfaction

• Male gender
• Being unemployed
• Low social integration
• Low mobility
• Poor perceived health

Predictors of High Satisfaction

• Female gender
• Being married
• Occupational independence
• Better current education level
• Longer time post-injury
• Less pressure ulcers

• Fewer rehospitalizations
• Lower level of injury
• Mobility independence (FIM)
• Sociocognitive independence (FIM)
• Increased social integration (CHART)


Other Predictors of Satisfaction

• Health competence
• Mood
• Family support
• Secondary impairments
• Activity limitations
• Participation restrictions


Other Predictors of Satisfaction

• Ventilator independence
• Lower levels of spasticity
• Good overall health
• Community setting
• Socioeconomic status


The Relationship of Life Satisfaction to Neurological Category and Time Post Spinal Cord Injury
Satisfaction With Life Scale


• Below are five statements with which you may agree or disagree. Using the 1-7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding. The 7-point scale is as follows:

1 = strongly disagree
2 = disagree
3 = slightly disagree
4 = neither agree nor disagree
5 = slightly agree
6 = agree
7 = strongly agree

__ 1. In most ways my life is close to my ideal.
__ 2. The conditions of my life are excellent.
__ 3. I am satisfied with my life.
__ 4. So far I have gotten the important things I want in life.
__ 5. If I could live my life over, I would change almost nothing.
10 years of Longitudinal SWLS

• 650 individuals contacted at one, five, and ten years post injury.
• Individuals were categorized by neurological category.
• All participants have data at each time point.
• Data was analyzed by a mixed model ANOVA.
<table>
<thead>
<tr>
<th>Neurologic Category</th>
<th>Year 1 SWLS (SD)</th>
<th>Year 5 SWLS (SD)</th>
<th>Year 10 SWLS (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Incomplete Paraplegia</td>
<td>19.9 (7.6)</td>
<td>21.2 (8.4)</td>
<td>22.7 (8.0)</td>
</tr>
<tr>
<td>Complete Paraplegia</td>
<td>19.0 (7.7)</td>
<td>21.3 (7.9)</td>
<td>21.8 (7.8)</td>
</tr>
<tr>
<td>Incomplete Tetraplegia</td>
<td>17.2 (7.3)</td>
<td>20.5 (7.7)</td>
<td>20.1 (8.3)</td>
</tr>
<tr>
<td>Complete Tetraplegia</td>
<td>17.5 (7.6)</td>
<td>20.8 (7.4)</td>
<td>23.0 (7.3)</td>
</tr>
<tr>
<td><strong>All SCI</strong></td>
<td><strong>18.4 (7.6)</strong></td>
<td><strong>21.0 (7.8)</strong></td>
<td><strong>21.6 (8.0)</strong></td>
</tr>
</tbody>
</table>
There was an interaction between Neurologic Category and Years Post-Injury
\[ F(6,1266)=3.05, p=.006 \]

There was a main effect for Neurologic Category
\[ F(3,633)=2.73, p=.043 \]

There was a main effect for Years Post-Injury
\[ F(2,1266)=67.16, p<.0016 \]
Findings

• Individuals with paraplegia differ from individuals with tetraplegia only at Year 1 (p<.05). There is no statistically significant difference at Year 5 or 10.

• There was no statistically significant difference for completeness at any time.

• Individuals with incomplete tetraplegia are scoring less than the other groups at Year 10 (p<.05).

• Over all time periods there was a significant effect for Neurologic category. Complete and incomplete paraplegics had higher SWLS than incomplete tetraplegics (p<.05).

• There was a significant effect for time, with significant increases at both year 5 and 10 (p<.005).
Cross sectional QOL data from 1 to 35 years post-injury

Santa Clara Valley Medical Center has contributed to the NIDRR-funded Spinal Cord National Database since 1973
Local SCI Dataset at SCVMC

- 1744 individuals have been enrolled and followed between 1973 and 2006

- Status at 2012
  - Deceased  602  (34.5%)
  - Lost       392  (22.5%)
  - Withdrawn  122  (7.0%)
  - Min/Normal 89   (5.0%)
  - Followed   539  (30.9%)
# Cross Sectional Data Y1-35

<table>
<thead>
<tr>
<th>Year Post Injury</th>
<th>SWLS N</th>
<th>Median SWLS Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>231</td>
<td>17</td>
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<tr>
<td>5</td>
<td>307</td>
<td>20</td>
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<tr>
<td>10</td>
<td>223</td>
<td>22</td>
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<td>15</td>
<td>173</td>
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<td>20</td>
<td>176</td>
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<td>25</td>
<td>191</td>
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<td>30</td>
<td>179</td>
<td>24</td>
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<tr>
<td>35</td>
<td>70</td>
<td>24</td>
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</table>
## Medians of SWLS items

<table>
<thead>
<tr>
<th>SWLS Item</th>
<th>Y01</th>
<th>Y05</th>
<th>Y10</th>
<th>Y15</th>
<th>Y20</th>
<th>Y25</th>
<th>Y30</th>
<th>Y35</th>
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</thead>
<tbody>
<tr>
<td>1. In most ways my life is close to my ideal.</td>
<td>3.0</td>
<td>4.0</td>
<td>4.0</td>
<td>4.0</td>
<td>5.0</td>
<td>4.5</td>
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<td>2. The conditions of my life are excellent.</td>
<td>3.0</td>
<td>4.0</td>
<td>5.0</td>
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<td>3. I am satisfied with my life.</td>
<td>4.0</td>
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<td>4. So far I have gotten the important things I want in life.</td>
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<td>5. If I could live my life over, I would change almost nothing.</td>
<td>3.0</td>
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Potential Predictors of SWLS at Y1-35

- Neurologic Category (Level and Completeness)
- Race
- Gender
- Age
- Marital Status
- Employment Status
- Education
- FIM/Functional Status
- CHART
  - Physical Independence
  - Mobility
  - Social Integration
  - Occupation
## Predictors of SWLS at Y1-35

<table>
<thead>
<tr>
<th>Var</th>
<th>Y01</th>
<th>Y05</th>
<th>Y10</th>
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Quality of Life Survey
Respondents

- N=53
- Mean age: 53.3 years
- 7-49 Years post injury
- 63% Male
- 87% Caucasian
- 49% Married; 36% Single
- 63% College or Advanced Degree
- 47% Working/productive activity; 29% Retired
- 53% Cervical Injury; 40% Thoracic
What had the most impact on your SWL immediately following your SCI?

- Support from family/spouse: 30%
- Friends: 16%
- Regaining independence: 12%
- Starting rehabilitation: 8%
- Returning to a career: 6%
- Good care from medical staff: 6%
What has the most impact now on your SWL?

- Support from family/spouse: 31%
- Friends: 18%
- Good health: 7%
- Maintaining Independence: 7%
- Faith: 6%
- Career: 6%
Survey Summary
SWL Measures

• Determinants vary person to person
  – Employment, Education, Personal/Social Relationships, and Overall Health

• Can either be objective or subjective
  – Functional performance, Expectations, Reactions to achievements
Commonly Used Measures

• World Health Organization Quality of Life Assessment (WHOQOL-BREF)
  – 26 items
  – Quick to administer
  – Culturally sensitive
  – Assesses a wide range of factors
  – Limited psychometrics in SCI
  – English only
Commonly Used Measures

• Sickness Impact Profile (SIP-68)
  – 68 items
  – Under 20 minutes
  – Yes/No format
  – English & Dutch
  – Available online
  – Limited psychometric testing in SCI
  – Contains walking assessment items
Commonly Used Measures

• Short Form Health Survey (SF-36)
  – 36 items
  – Under 10 minutes
  – Numerous languages
  – Available in shorter SF-12
  – Contains items to assess climbing and walking
Commonly Used Measures

• Craig Handicap Assessment and Reporting Technique (CHART)
  – 26 items
  – Culturally sensitive
  – Assesses multiple domains
  – Limited psychometrics in SCI
  – English only
Commonly used Measures

• Life Satisfaction Questionnaire (LISAT-11)
  – 11 items
  – Wide range of domains
  – Public domain
  – 8 Languages
  – High reading level
  – Little psychometric information in SCI
Commonly used Measures

• Quality of Life Index (QLI)
  – 32 items
  – Under 10 minutes
  – 4 subjective domains
  – Downloadable
  – SCI-specific version
  – Little psychometrics
  – English only
Commonly used Measures

- Quality of Life for Adults with Physical Disabilities (QOLP-PD)
  - 102 items
  - Early stages of development
  - Available from author
  - Psychometric testing needed
  - English only
Further information

• SCIRE website: http://www.scireproject.com/
