Response Shift in Veterans and Civilians with Neurogenic Bowel and Bladder Following Spinal Cord Injury

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Disclosures

Dr. Edward Rohn has no financial interest to disclose.

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Learning Objectives

1. Recognize how the response shift model captures different individualized experiences in adjustment to SCI-related neurogenic bladder and bowel.

2. Identify patterns of associations between response shift and quality of life among veterans and non-veterans with SCI.

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Defining the Problem:
Neurogenic Bowel and Bladder after SCI and Implications for Quality of Life

• Loss of bowel and bladder functions after spinal cord injury (SCI) can significantly alter one’s ability to function and impacts quality of life (QOL).
  – Physical Independence
  – Sexuality and intimacy
  – Employment and economic stability

• Bowel incontinence is also the greatest source of social discomfort after SCI

Burns et al. 2014
Measuring Impact on Quality of Life

• Measuring these negative effects on QOL and understanding their relation to adaptation are critical in formulating new treatments.

• QOL can mean many things to different people thus measuring it can be difficult.

• Patient self-report is most desirable; suggest phenomenological approach

• Response Shift theory can assist QOL appraisal.

Rapkin and Schwartz, 2004
Study Aims

• Review data from persons with recent and long-term SCI both civilians and military backgrounds.

• Compared their experiences in the context of life adaptation after SCI and their loss of bladder and bowel function.

• Investigated the associations between response shift and QOL definitions.
Defining Response Shift

• “When individuals undergo a change in health status, they may change their internal standards, their values, or their conceptualization of QOL”. Schwartz 2000

• The RS theoretical model includes:
  – catalysts (SCI)
  – antecedents (personal characteristics)
  – mechanisms (processes to accommodate changes in catalysts)
  – response shift (change in self-evaluation, internal standards, values)
  – perceived quality of life (key outcome of the above components)
Response Shift and Quality of Life Model

Figure 1
Sprangers and Schwartz (1999) theoretical model of response shift and quality of life
Does Response Shift provide a conceptual model to explain QOL appraisal after loss of bowel and bladder functions?

Factors
- Military Status
- Time Since Injury
- Age, neuro level
- gender

Response Shift
- Reframing
- Internal comparisons
- Goal adjustment

QOL Appraisals
- positive
- negative
Mixed Methods Methodology:

- Qualitative interviews were conducted with 40 SCI participants
- Study team read transcripts for evidence of RS based on 3 criteria:
  - 1) change in internal standards (recalibration)
  - 2) change in values
  - 3) redefinition of QOL construct

Analysis Approach 1

- A scoring system for RS was developed from 0-2; applied with inter-reliability checks
  - 0 showed no RS
  - 1 showed partial response (one aspect)
  - 2 showed full response shift (two or more aspects)

- RS scores were compared to QOL ratings (0-10) and Matrices were developed showing quotes, RS and QOL

Analysis Approach 2

- Themes were identified through pile sorting into 4 categories of RS:
  - 1) behavior-driven
  - 2) awareness-driven
  - 3) social comparisons
  - 4) resignation
Quantitative Analyses

• Full group statistics were calculated across all QOL measures and indicators:
  – PROMIS
  – SCI-QOL

• Comparisons were made between RS and QOL for key attributes:
  – 1) civilians and military veterans
  – 2) recent and long-term injury
  – 3) age, gender and neurological impairment level
# Sample Characteristics (n=40)

**Mean Age:** 52.5

<table>
<thead>
<tr>
<th>Category</th>
<th>Subcategory 1</th>
<th>Subcategory 2</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td>Males N=32</td>
<td>Females N=8</td>
</tr>
<tr>
<td><strong>Veteran Status</strong></td>
<td>Veterans N=22</td>
<td>Non-veterans N=18</td>
</tr>
<tr>
<td><strong>Time since Injury</strong></td>
<td>Injured &lt;1yr N=10</td>
<td>Injured ≥10yrs N=30</td>
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<tr>
<td><strong>Level of Injury</strong></td>
<td>Complete paraplegia N=17</td>
<td>Complete tetraplegia N=6</td>
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<tr>
<td></td>
<td>Incomplete paraplegia N=6</td>
<td>Incomplete tetraplegia N=11</td>
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<tr>
<td></td>
<td>Total paraplegia N=23</td>
<td>Total tetraplegia N=17</td>
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</table>
## Individual Quotes: Behavior Driven RS

<table>
<thead>
<tr>
<th>Antecedents</th>
<th>Mechanism</th>
<th>Response Shift Indicator</th>
<th>Quality of Life Appraisal</th>
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</table>
| White male, 56 years old, single, 37 years post SCI, complete tetraplegia, lives alone, car flipped over his vehicle, veteran. | ...my coping skills and my attitude...I was always a positive person, I go see people in hospitals in worse situations...so I controlled the injury, didn’t let control me. | I was devastated at first...then you move your goals and get on with your life again... I’ve learned a lot about myself... Employed as director of a SCI organization | QOL rating = 9
It’s not perfect and a lot revolves around bowel issues. |
| White female, 27 years old, 1 year since injury, incomplete tetraplegia, diabetes ketoacidosis, led to stroke to the spinal cord. | Things happen for a reason, God wanted me to go through this process. Maybe I will learn something... I am very determined. | Everything just changes... you start to appreciate things better... I’ve picked new hobbies like painting at therapy which I never did before | QOL rating = 7.5
I try to see the positive in anything and my hands are moving more now... So I’m not the best but I’m not the worst. |
### Individual Quotes: Awareness Driven RS

<table>
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</thead>
<tbody>
<tr>
<td>Black male, 62 years old, 28 years post SCI, unemployed, paralyzed via gunshot, has 3 sons Complete paraplegia Credits the VA with taking good care of him</td>
<td>When I got shot I had a good attitude, a friend of mine taught me about being paralyzed. My survival skills I had to learn when I was in the infantry... I believe in Jesus</td>
<td>I am adjusted to this. I accepted the position because it could be a lot worst... I still knew who I was in the wheelchair. It was not like I’m living it, I’m just using it.</td>
<td>QOL rating = 10 That I’m still alive and still in my right mind... it is a good thing. A lot of people did not wake up this morning; they did not wake up in the right mind either.</td>
</tr>
<tr>
<td>Black male, 48 years old, 16 years post, incomplete tetraplegia, auto accident, Veteran, married, 3 adult children, can walk a few steps</td>
<td>Early on was quite overwhelming, so there is a lot of exploration in your mind, wondering a lot. I was raised a Baptist, it was a spiritual journey for me. Having a strong intact family has been a source of comfort.</td>
<td>My situation could have been much worst... and coming to a place psychologically, this was the problem and the key, to understanding that being in a wheelchair does not make me less of a man.</td>
<td>QOL rating = 9.5 Just the place I am now, I’m happy. I’m in a place where I can give back. I can give to others and make a difference.</td>
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## Individual Quotes: Social Comparisons

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<tr>
<td>White female, 55 years old, 1 year since injury, incomplete tetraplegia, retired police officer, married, spinal abscess, of sudden onset</td>
<td>I marveled at the ones that would get up, get dressed and make it to work every morning... and for me as much as I would like to do things like that, “Well would you rather been blind...” You take what you can get.</td>
<td>Initially it was so hard...I guess, a lot more just because of bowel...now I can get up and get going. My life goal is to be happy and healthy and I am... I could have gotten shot and killed 20 years ago...</td>
<td>QOL rating = 9.5 ...is there anything I could be doing to enhance my situation to make it better, to make me stronger... my goals aren’t changing... my sense of self, I’m still very confident...</td>
</tr>
<tr>
<td>White male, 56 years old, 37 years post, injured by fall, retired computer programmer, incomplete tetraplegia</td>
<td>I go to church every now and then. I also volunteer, if someone asks me for help I help them...just an everyday thing...</td>
<td>I don’t think I went through a lot of traumatic experiences learning as some other people did...it’s got to be what it’s got a be...I accepted and want to do what I have to do to get on with life I guess</td>
<td>QOL rating = 8.5 It could be a little better. But overall, everyday I say a prayer and I thank God for the life I have, for my family and my friends. I am happy despite my injury, I think I got it pretty good</td>
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### Individual Quotes: Resignation and Despair

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<tbody>
<tr>
<td>White male, 64 years old, 45 years since injury, complete paraplegia, veteran injured in car accident, while in active duty, divorced, never worked, lives alone, step father to 3 sons</td>
<td>It was pretty devastating but I had no choice and I had to adapt... just put everything out of my mind and got into drugs the first couple years... Accept it and move on... but it’s to the point where it doesn’t really matter anymore.</td>
<td>I calmed down a hole lot actually a long time ago... just growing up, I guess... Well I really had no idea. I just accepted my situation. It is all out of my control and there was nothing I could do or say to make any difference. It’s either hang in there or die.</td>
<td>QOL rating = 9 Well, it’s because I don’t care anymore. I’m not depressed. I accept my life, that’s all... Well it sucks. It’s a struggle, but it’s ok... Yeah I just live with it.</td>
</tr>
<tr>
<td>White female, 36 years old, 1 year post SCI, car accident, complete paraplegia, fiancée is caregiver, has some bowel sensation</td>
<td>You have to rely on somebody to get you, you have to take pills to go poop... It’s very hard for my family, I guess</td>
<td>Basically, I am starting over... you know just because I’m paralyzed there just a new way of doing things. The doctors need to work on some stuff and give me my legs back...</td>
<td>QOL rating = 5 Because it’s not bad and it’s not good. You make it out what it is... waking, being able to drive, doing things I used to do... my dreams got taken away and my husband’s did too; all of them.</td>
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Response Shift Analyses:

*RS Groups to PROMIS and RS Ratings*

- Those in the *social comparison* group had the highest scores in the PROMIS Global Mental Health (p<.024) with those in the resignation group having the lowest scores.

- Those in the *resignation group* had the lowest scores in relation to PROMIS Global Physical Health, SCI-QOL Bladder management, SCI-QOL Bladder Complications, SCI-QOL Bowel Management, SCI-QOL positive affect – but data only approached significance.

- Those in the *behavior* and *awareness driven* groups had the highest response shift ratings (p<.005); these groups also rated their QOL higher (p<.05).
Response Shift Analyses:

Data Trends Among Sample Attributes

• There were no differences based on gender or age but there were differences in terms of time since injury. More people with longer TSI had full response shifts (53%), often behavior or awareness driven.

• There was only a trend in terms of RS scores related to military status. All people with no response shift served in the military but also more people in the military had full response shift. (p<.10)
Response Shift Analyses: 

Data Trends Among Sample Attributes

- All people with incomplete paraplegia had some response shift (RS) while the majority of those with tetraplegia had full response shift ($p<.06$)

- There were no differences in RS ratings when compared to difficulties managing bladder or bowel.
Response Shift Analyses:

*RS Ratings as Compared to QOL*

- RS ratings were significantly associated with QOL self-reported ratings ($r=.43; \ p<.006$)

- Groupings by RS tended to be associated with QOL. Those in the behavior and awareness driven groups had the highest QOL scores ($p<.06$)

- QOL ratings were higher for those with longer time since injury ($p<-003$)

- PROMIS: There were significant differences in the Global Physical Health and Depression scores as a function of RS ratings – those with no RS had the lowest scores.
Conclusions

• Persons with SCI experience different paths in their life trajectories, suggesting differences in QOL and adaptation to SCI.

• These trajectories have implications for long life adaptation and readiness to change, also having an effect on QOL and overall health.

• A Response Shift model can be used to explain these trajectories and health/disability outcomes including perceptions of QOL.

• These data can help clinicians to understand/conceptualize the challenges patients face and why responses to treatment may be more/less effective.

• The relationship of bowel and bladder dysfunction with RS ratings was unclear. While not associated with RS, the impact of bowel on QOL was inversely related to PROMIS Global Physical Health (p<.033) suggesting that bowel dysfunction impacts QOL.
Moving Forward

• Intend to explore these issues in more depth to provide clearer explanation of trends

• Connect RS scores to rates and severity of complications and bladder-bowel management challenges.

• Future research will focus on patient agency in adapting/responding to health circumstances
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