Bladder and Bowel Dysfunction and their Impact on Wellbeing and Quality of Life

Putting the Patient in the Driver’s Seat

Denise G Tate PhD, ABPP

dgtate@umich.edu

https://medicine.umich.edu/dept/pmr/research/research-areas/spinal-cord-injury-research
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Acknowledgments - Collaborators

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Michigan Spinal Cord Injury Research Team
Presentation Outline

• Describe the problem: neurogenic bladder and bowel (NBB) and findings on quality of life and wellbeing
• Discuss patient behaviors in relation to autonomy and decision making
• Present patient testimonials
• Share my own studies research findings
• Conclusions and recommendations

Throw some challenges to clinicians and researchers
Presentation Assumptions and Goal

1. Changes in patient behavior are key to the success of treatments for neurogenic bladder and bowel dysfunction.
2. Behavior occurs in the context of many other factors.
3. Putting the patient in the driver’s seat will enhance our ability to be successful in treating these problems and of improving quality of life.
4. My intention today is to show you why I believe this so important.
Bladder and Bowel Dysfunction after Spinal Cord Injury and their Impact on Wellbeing and Quality of Life

Studies on Aging and SCI

Prevalence Rates for 16 Comorbidities in a Michigan Sample (n=125)

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Arthritis</td>
<td>40%</td>
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<tr>
<td>Hypertension</td>
<td>39%</td>
</tr>
<tr>
<td>Hyperlipidemia</td>
<td>29%</td>
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<tr>
<td>Overweight</td>
<td>27%</td>
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<tr>
<td>Depression</td>
<td>24%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>15%</td>
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<tr>
<td>Osteoporosis</td>
<td>12%</td>
</tr>
<tr>
<td>Asthma</td>
<td>10%</td>
</tr>
<tr>
<td>Cancer</td>
<td>9%</td>
</tr>
<tr>
<td>COPD</td>
<td>7%</td>
</tr>
<tr>
<td>Stroke</td>
<td>5%</td>
</tr>
<tr>
<td>Cong Heart Failure</td>
<td>3%</td>
</tr>
<tr>
<td>Cor Artery Disease</td>
<td>3%</td>
</tr>
<tr>
<td>Chr Kidney Disease</td>
<td>3%</td>
</tr>
<tr>
<td>Dementia</td>
<td>2%</td>
</tr>
<tr>
<td>Dementia</td>
<td>1%</td>
</tr>
</tbody>
</table>
Health Changes in Relation to the Living Environment

• The role of social environmental factors in determining health, contributing to disease and disability has been acknowledged by the scientific community around the world. (WHO Report on Disability, 2015)
• We live in a dynamic and interactive world through which our personal experiences are filtered and shaped.
cells

behavior

environment
Peeling the Layers: Understanding the Context

- Social context
- Psychological issues- Emotional Coping
  - Embarrassment
  - Shame
- Cognitive appraisal
- Problem solving

How to best address bladder problems?
What is the problem?

Excerpts from the scientific literature

- Improving bladder and bowel function is rated as one of the highest priorities among persons with SCI. Andresen 2004, Tulsky et al. 2015.

- Risk factors to bowel complications include age, time since injury, neurological classification, race, access to caregivers, diet, use of medications, etc. Tate et al. 2016.

- Despite the high frequency of bowel and bladder complications, there are very few controlled studies in the literature. Tate et al, 2015; Cameron et al., 2015.
The Scope of the Problem

• ...if you let your bowels stress you out, you are giving your control away to them.

38 year old Zachary Young
Bowel Dysfunction Impacts Quality of Life

www.msktc.org/sci/videos

PHYSICAL MEDICINE & REHABILITATION

MICHIGAN MEDICINE
UNIVERSITY OF MICHIGAN
Research in Neurogenic Bowel and Bladder After SCI

• Improving bowel function alone is rated as one of the highest priorities among individuals with SCI (Glickman & Kamm, 1996; Anderson 2004)

Video courtesy: https://msktc.org/sci/Hot-Topics/Bowel_Function/managing-Bowel_Function

Marva Ways, Tom Hoatlin, Zach Young, 2016
The Complexity of the Problem: Finding Solutions

• Each person has very special needs and maybe facing a number of compounding issues.
• Many times there is no easy solution.
• How can we best guide our patients in finding the best solution?
Bladder and Bowel Dysfunction after Spinal Cord Injury and their Impact on Wellbeing and Quality of Life

Research Findings: Quantitative and Qualitative

- What are the main risk factors and complications?
- How do patients perceive/experience Complications and methods of management?
- How do patients make decisions?
Bladder Complications (n=300)

% of Subjects Reporting Bladder Complications

- Urinary Incontinence Monthly: 58%
- Kidney Stones Past Year: 8%
- Bladder Stones Past Year: 4%

Research support from NIDILRR
Urinary Tract Infections (UTIs)

• 56.4% had at least one treated UTI during the past year.
• Factors associated with UTIs: older (>55), female, employed, complete injuries, used opioids, also had bowel incontinence.
• Fear of re-infection by catheter was mentioned in several cases impacting decisions of bladder management method.

“\textit{I try not to cath because I have gotten UTIs and stuff from cathing}” 35yr old woman, 19 yrs post

Tate et al., 2017; Forchheimer and Tate, 2018

Challenge #2
Bowel Complications (n=535 responses)

% of Responses from Subjects Reporting Several Bowel Complications

- Abdominal Bloating: 25%
- Liquid Incontinence: 23%
- Solid Incontinence: 20%
- Abdominal Pain and Discomfort: 6.5%
- Chronic Constipation: 25%
Risk Factors for Bowel Incontinence

- Irregular timing of bowel program
- Presence of constipation
- Lack of caregiver help
- Excessive use of diuretics
- Greater bowel dysfunction as measured by NBD
- High frequency of urinary incontinence.

Tate et al, 2016.
Impact of Bowel Dysfunction on Quality of Life (n=194)

- No impact: 9%
- Little impact: 33%
- Some impact: 30%
- Major impact: 27%

Bladder and Bowel Dysfunction after Spinal Cord Injury and their Impact on Wellbeing and Quality of Life
How much can you fit your life around your bladder and bowel management routines?

![Bar Chart](chart.png)
Experiencing QOL After NBB

- Behavior is shaped by our experiences.
- Understanding behavior in the context of stressors being faced.
- Leakage impacts quality of life.
Conceptual Models of Coping

• Understanding coping help us understand behavior.
• Stress, Appraisal and Coping Model by Lazarus and Folkman.
• Response Shift Model by Schwartz
• Appraisal influences coping behaviors which in turn impact psychological wellbeing and QOL.
  • Primary appraisal – threat, loss of function (i.e. loss of continence)
  • Secondary appraisal – how to manage the situation, resources
Coping and Adjustment Model for SCI

Pre-injury Factors

SCI

How a person perceives their situation and how they perceive their ability to cope

Manage able

Positive Coping Strategies

Positive Outcomes

Avoidance Coping Strategies

Unmanage able

Negative Emotional Impact

Secondary Complications

Duff and Kennedy, 2003
A Response Shift Model of Adaptation to Changing Health

- Response shift (RS) refers to changes in internal standards, values, and conceptualization of quality of life and wellbeing. (Schwartz et al., 2005)
- These behavioral changes are referred to as recalibration, reprioritization, and reconceptualization of RS.
Qualitative Research Data (n=40)
Behavioral Changes in Adaptation to Bladder and Bowel Complications

- Patterns of behavioral adaptation reflecting responses to complications were identified.
- These were classified (pile sorted) into 4 groups of responses from most adapted to least
  - **Behavior driven changes** (taking an active role in responding to complications) - G1
  - **Awareness driven changes** (focus on sense of self-identity and threats to health) - G2
  - **Social comparisons** (comparing circumstances to others) - G3
  - **Resignation and despair** (being “stuck” or giving up) - G4

Research support from US Dept. of Defense
Narratives on Complications and QOL from Groups 1 and 4 by *Response Shift Stages*

<table>
<thead>
<tr>
<th>Personal Characteristics Antecedents</th>
<th>Problem Appraisal Mechanisms</th>
<th>Problem Response Response Shift</th>
<th>Quality of Life Rating QOL</th>
</tr>
</thead>
<tbody>
<tr>
<td>G1 - White male, veteran, 69 year old, 27 years post SCI, Complete Paraplegia, with caregiver.</td>
<td>Sometimes it {bowel incontinence} just hits you all at once like the flu or diarrhea... Then you got it all over and you have to take your clothes off and clean yourself...</td>
<td>I do digital stim and make sure I emptied myself so that way I have a better chance of not having an accident during the day...and try to stay away from certain kinds of foods...</td>
<td>...I won’t say 10 because it’s senseless to say that you’re a 10 when you are in a wheelchair...Well I picket a 7 because it’s not just so-so ...but that to do {with} the bladder and your urine and everything like that.</td>
</tr>
<tr>
<td>Methods: Self Intermittent Catheterization; Digital Stimulation, Digital Evacuation.</td>
<td></td>
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<tr>
<td>G3 - White male, veteran, 64 years old, 21 years post-SCI, Incomplete Tetraplegia, no caregiver.</td>
<td>It’s a pain in the neck. I never know what’s going to come out of either end or when. Sometimes my...bladder just spurts it out and leaks all over. As far as my other end, I’m constantly constipated or like yesterday...everything I’ve been taken loosened everything up...</td>
<td>Most of the time my clothes smell like urine from leakage...and I can’t control it. I had to go {bowel movement} 3-4 times and ended up canceling a visit with my brother because I thought I was going to have diarrhea.</td>
<td>I like my life. Everything would be great if I didn’t have bladder and bowel problems. My work, getting in to visiting with people who are at the end of their life and being part of who they are and what they do...God gives you the grace to do it, to do what he asks you to do. QOL=8</td>
</tr>
<tr>
<td>Methods: Self Intermittent Catheterization; Straining, Meds. Employed as a Priest.</td>
<td></td>
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Growing Interest in DM Research in SCI

- Better understanding the context of patient decision making
- Preferred and actual roles
- Factors influencing their treatment of choice

Research supported by the US Dept. of Defense
Many (50%) participants self-initiated changes in their methods of management to solve bladder and bowel complications.

These decisions resulted in positive behavioral outcomes (increased QOL, satisfaction, proactivity, participation) and fewer complications (i.e. incontinence, UTIs, etc.).
## Examples of Decision Making Resulting in Changes in Methods of Management and Positive Outcomes

<table>
<thead>
<tr>
<th>Problem with Complications</th>
<th>Change in Method of Management</th>
<th>Outcomes</th>
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</thead>
<tbody>
<tr>
<td>UTI, bladder incontinence/leakage.</td>
<td>IC to Urinary Diversion/Ostomy. I did IC for three years.</td>
<td>“I think it’s better. It’s been a ton better...I’ve gotten very few UTIs since. Maybe once a year, as opposed to once every 3 months when I was intermittently cathing” QOL rating= 8.5</td>
</tr>
<tr>
<td>UTI and bladder incontinence/leakage.</td>
<td>Normal voiding to IC</td>
<td>“It made a big difference for me because it has allowed me to manage my bladder much more regularly...(and) cut down on...UTIs. It’s given me a lot of independence that I hadn’t even considered before.” QOL rating = 9.5</td>
</tr>
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| Challenge #3 |
Summary of Findings:
DM in Bladder Dysfunction and QOL

- The choice of bladder management is based on its impact on QOL.
- Methods that promote greater control and independence while minimizing complications such as incontinence or UTIs are often preferred.
Important Factors Considered

• Treatment convenience – can do it myself, faster, economical, easy to use, no risk
• Health professional influences – opinions
• Social influences – family support, peer experiences, social activities
• Physical attributes – ability (hand control), sexuality
• Psychological attributes – embarrassment, confidence, satisfaction

(Engkasan et al. 2013)
Conclusions: Linking Evidence to Action

• QOL studies are a way to value the perceptions and grant the individuals respect and expand the professional understanding of the patients’ perceived position in life, their cultural system, values, objectives, concerns and environment.  

Fumincelli et al. 2017
Supporting Patient Autonomy and Decision Making

• Patient centered treatments improve satisfaction and engagement.
• Value on patient’s ability to make choices.
• The role of clinicians: to enable patients make decisions.
• Nurses roles in education
• Empowerment of patients promotes better outcomes.

Patients are the drivers of change
Implications for Clinical Practice and Future Research
Implications for Clinical Practice

• Interventions providing training on positive appraisal and successful coping strategies are critical for those experiencing new medical complications related to NBB.

• To to be effective, these interventions should emphasize patient’ input and control so they are truly relevant in addressing their needs.

• Patient-provider communication and education through positive interpersonal alliances, building mutual trust and are more likely to result in successful treatments.

Thank you for your attention!
Implications for Research

- Longitudinal studies tracking life trajectories of those aging with NBB and outcomes.
- Clinical studies focusing on effective coping, self-efficacy and self-management.
- Studies focusing on new technologies for NBB are also in demand.
- Studies on successful treatment for bowel complications and methods are especially needed.
Bowel Dysfunction and QOL

• The fear of incontinence and inability to plan ahead daily activities

• Problem solving: Colostomy

Final Challenge