

Outcomes are the Changes You Expect to Result from Your Program

In the July issue of our newsletter, we discussed factors influencing decision making related to bladder and bowel problems. In August's publication, we focused on the challenging process of making these decisions; having to consider medical choices and the availability of needed resources. This newsletter describes findings regarding varied outcomes from these decisions.

We considered two main outcomes: satisfaction with your decision and how this decision has impacted your quality of life (QOL). Along with seeing the study results here, you will meet Laura Jackson and Barbara Schoen PhD who openly reveal their perspectives on decisions and outcomes related to their own bladder and bowel complications. Woven throughout this newsletter's additional articles, several participants also comment on their decision outcomes.

We defined *outcomes* as changes you could expect of what was done or undone to address these bladder and bowel complications. This included changes in methods of management, medications, surgical procedures, arrangements with caregivers, and availability of resources.

In our previous issue, the consumer guides for bladder and bowel from the Paralyzed Veterans of America (PVA) were highlighted. We recommend that you review these as they, too, provide many tips about how to best manage your bladder and bowel after SCI.

DECISION MAKING ABOUT SCI

How to Best Manage Bowel and Bladder Issues After Spinal Cord Injury

Our Succession of Studies Yields New Knowledge About Decision Making and SCI Outcomes

By: Denise G Tate PhD, Professor of Physical Medicine and Rehabilitation and Project Director

Our previous study in 2012 inspired some of our current questions regarding outcomes from decision making related to neurogenic bladder and bowel after SCI.

Those earlier findings suggested the importance of healthy social participation and a greater sense of wellbeing as highly valued outcomes from successful resolution of complications related to bladder and bowel, including new methods of management.

Previous findings also suggested greater self-efficacy and improved satisfaction with care following appropriate decisions related to undergoing surgical procedures. These procedures involved changing methods of bladder or bowel management by having a suprapubic reconstructive operation, or a colostomy, for example.



Denise G. Tate PhD, is a Professor and Psychologist in the U-M Department of PMR with years of experience in SCI.

In both cases, having greater ability to catheterize or conduct one's bowel program with less time involvement were seen as satisfactory solutions to these problems.

In terms of managing bladder complications, intermittent catheterization was by far the most often used method of management, but it posed problems for both veterans and civilians with recurrent urinary tract infections (UTIs), leading some to question their bladder management methods:

"My bladder started getting a thick wall because it was pushing out and forming a muscle...and I was getting lots of infections...so I went to a suprapubic."

Previous study participants spoke of their frustration levels, stress and fears about intermittent catheterization and bowel incontinence episodes. Bowel incontinence was a frequent problem that led veterans to question their bowel management programs:

"I have no real outside life due to concerns over accidental bowel movements. So, I am putting in to get an elective colostomy done."

While these observations resulted from our previous study findings, we were unable to link these outcomes to the decision making process itself.

Our goal with this study, which started in 2017, was to determine if these decisions, once implemented, would result in positive health and QOL outcomes.

The current study examined decisions related to changes in bladder and bowel methods of management and complications and their effect on QOL outcomes.

To measure QOL outcomes, we conducted a thematic analysis from participants' narratives identifying themes and patterns in the data. We collected QOL ratings and ratings of satisfaction with decisions made related to bladder and/or bowel.

We also used several standardized measures to assess QOL, decision making, satisfaction and other psychosocial characteristics such as mental health, self-efficacy, and social support.

A Word from the Wise: **Comments on Decision Making from an Expert in SCI care**

Frederick M. Maynard, MD served as the first Principal Investigator and Director of the U-M SCI Model Systems. During his years at Michigan Medicine, he treated many inpatients and outpatients with SCI and with his team he led several research projects. Dr. Maynard is now retired and lives in Marquette, Michigan.



After reading our second newsletter, he offered the following comments about our newsletters and the process of decision making:

"I wanted to send you my congratulations for producing such an interesting and informative resource that should prove helpful to many SCI patients and professionals."

I especially like the idea of breaking down decision making into two psychological concepts of cognitive appraisal and coping. I think we used to refer to cognitive appraisal as 'information seeking' and certainly many people are truly overwhelmed in the early days after SCI such that they are little able to engage in their own cognitive appraisals of the many facets of the medical decision making that must go on, and to which they later (hopefully) will be offered an opportunity to be actively involved with."

Thank you, Dr. Maynard, for your kind and insightful words. Indeed, decision making is a complex process requiring simultaneous evaluation of so many factors that may influence one's quality of life and wellbeing after a decision is made. It is truly an overwhelming process to undertake right after injury when one is still trying to adjust to the many changes in life.

Coping with the emotions of loss take priority over cognitive appraisal at its best. This is especially the time when approaches like shared decision making can enable both the newly injured person and his/her medical team to jointly initiate the first steps toward recovery. Together they can demonstrate options and help make choices that prove to be informative and educational for the person with SCI; while also empowering the person to begin making new decisions that will ultimately bring about feelings of dignity, respect, autonomy, and personal satisfaction.

--Denise G Tate, Psychologist and Project Director

Difficult Decisions, Important Outcomes:

Laura Jackson Discloses Her Personal Experience

Interviewed by: Denise G. Tate



My name is Laura Jackson. I am a 33-year-old woman with a C1-C2 injury since 2003. I'm a ventilator dependent, quadriplegic and use a power wheelchair.

I enjoy spending time with family and friends, going to concerts, sporting events, and trying new restaurants. I serve on the Board of Directors for an incredible nonprofit called Mi Work Matters. Their mission is to find meaningful employment for people with intellectual and developmental disabilities. I also serve as the Co-Vice President of the Young Professional Board for the nonprofit North Star Reach. The camp is Michigan's only barrier-free, fully accessible medical camp serving children with significant health challenges and their families, at no charge to them. I feel honored to be a part of these organizations and to give back to the disability community.

Interviewer: Would you provide me with an example of a difficult decision you had to make in this respect (either bowel or bladder) and its outcome?

Laura: A difficult decision that my parents and I had to make regarding my bladder was whether to get the suprapubic catheter. I ended up getting the tube placed and it has been an incredible decision!

Interviewer: Was this outcome satisfactory to you? Why so? Would you do it again?

Laura: Having the suprapubic tube allows me to have more freedom to continue moving into my day's activities without interruptions. My quality of life definitely improved after getting it.

Interviewer: How did this outcome impact your current lifestyle, ability to be independent, overall happiness and quality of life?

Laura: I like that I do not have to use public restrooms that aren't usually set up for power wheelchair users and privacy. I also have found that my UTIs have been limited since getting it, as well. I am happy that I do not have to worry as much about having accidents and taking time out of my day to catheterize.

Although this decision seemed scary at the moment, it has been a life changer for me, and I would absolutely do it again!



"I choose to honor this beautifully broken body. It has and continues to serve me in ways I never thought possible after breaking my neck."

What Happens after Making the Decision?

Reflecting on the Benefits of SCI Decision Making

By: Edward Rohn, Ph.D.

Our research showed a number of important outcomes of the decision making process, leading to changes in day-to-day life for many. These changes might be unexpected and beneficial if you're considering your own change in management. While not every participant in our study had positive feelings and experiences from their decisions, the clear majority did. **The goal here is to share some of these positive experiences from our study.**

About half of our participants reflected on the beneficial medical outcomes of their new management approach. People reported that their complications--like UTIs and constipation--improved. Management itself became easier, less time consuming; and left them feeling better overall. Below is a quote from one participant who opted for both ileostomy and colostomy surgeries to help their bladder and bowel management respectively:

"Definitely with the bowel and the urine and the UTIs and stuff... this year, I was doing pretty good with it. I haven't been hospitalized for either one... so, it's definitely been a blessing and it's definitely been a relief."

While we anticipated that these kinds of medical benefits would be clear from our research, many talked about the psychological and social benefits of their decision; in fact, more referred to these benefits than referred to their medical improvements. Many felt more hopeful and self-confident. Others reported being able to go out and participate more easily and experienced greater independence. Next is a quote from someone who began intermittent self-catheterizing, after a long use of a Foley bag. He commented on another important element: feeling "more normal."



"To me, it's more about being able to do things I wanna do and whatever makes it easier... I mean you look a little more normal like this. Nobody knows."

Overall, the majority of people in our research were satisfied with the results of their decisions. They commented on how effective their new method was and the pluses they experienced in their daily lives. They felt empowered. People could participate socially more and experienced more freedom. Below is a quote from another participant who adjusted his approach to catheterizing:

"I'm happy I made the decision. It just uh, works, works nicely for me. When doing it that frequently, it makes your whole day just that much better."

In the end, the quality of life of many participants improved because of their decisions. Once the careful decision making steps were taken, as described in the previous issues of this newsletter, many people experienced new advantages--potential benefits worth remembering as you consider your own management choices.

"It has Simplified My Life"

Barb Schoen Discusses Options, Informed Choice

Interviewed by: Denise G. Tate



I am Barb Schoen, an Associate Professor at the College of Counseling and Rehabilitative Sciences at the University of Texas-Rio Grande Valley since 2017. Since my C5-7 spinal cord injury in 1997, I obtained my master's degree in Rehabilitation in 2003 and doctorate in Rehabilitation Counselor Education from Michigan State University in 2010. Between degrees I completed a two-year internship at the U-M Model Spinal Cord Injury Care System and credit Dr. Denise Tate for prompting me to pursue my PhD.

As an educator and researcher, I have received funding through The National Institute of Health, National Library of Medicine and Department of Education totaling over \$1,000,000, taught over 20 courses and have numerous publications in peer-reviewed journals with a focus on consumer advocacy. In my private life I enjoy literature, art, music and theater.

Interviewer: Would you provide me with an example of a difficult decision you had to make in this respect (either bowel or bladder) and its outcome?

Barb: In 2005, I consulted the U-M Department of Urology on a unique urinary diversion that created a canal from my bladder to my stomach using bladder tissue. This allows me to catheterize through this opening that mirrors the function of the urethra.

Interviewer: Was this outcome satisfactory to you? Why so? Would you do it again?

Barb: Almost 25 years later I am relatively free of infection and have had little to no complications. I consider this a life changing intervention as I found traditional catheterization through the urethra and an indwelling catheter problematic for a variety of factors. I have not had any diversion of my bowel but have spent over 20 years fine-tuning the process. I credit probiotics, laxatives and suppositories to program success. I would urge folks to experiment to see works best for them and consider circling back. I currently complete my bowel program in bed and usually self-evacuate with the help of a suppository. *This did not work for me early on*, and may not work for others, as gravity does help the process.

Interviewer: How did this outcome impact your current lifestyle, ability to be independent, overall happiness and quality of life?

Barb: I am thankful that I tried something that didn't work for me initially because now it has simplified my life.

In summary, I would speak to professionals, peers and read existing research on viable options so that you're able to make an informed choice.



I appreciate what Robert Schuller once said:

'Let your hopes, not your hurts, shape your future.'

Barb (left), with her sister, Peg

Project Participants Offer Insightful Answers

Satisfaction with Decision Outcomes and Quality of Life

Overall, our study participants were satisfied with their decision outcomes. Their ratings of QOL were associated with satisfaction with these decisions. Those satisfied with their bladder and bowel decisions had higher scores in coping strategies based on seeking social support. In other words, those happy with their decisions also used seeking social support as an effective coping strategy to address their problems. Satisfaction with decisions was also associated with better mental wellbeing and social participation ability. Those more satisfied with the bowel management methods also reported greater satisfaction with their decisions.

Participants' Impressions about Rating Decisions, Veteran Status

Most participants in our study (77%) rated their decision outcomes as an 8, 9 or 10 (being the highest rating). In providing reasons for these ratings, they evaluated the pros and cons of each decision outcome. Several provided us with insightful answers:

Some participants provided thoughts on their veteran status and their benefits:

"Well, yeah, because like we said, before I was paying my way. And to know that you had 100% dedication to your situation by an organization is...that's almost like a godsend to me."

Another participant talked about the military's influence on his ability to make decisions:

"Um, I think the military status taught me how to make quicker decisions. You gotta make quick, fast decisions. You have to work the system--instead of fight the system. That's what you learn in the military."

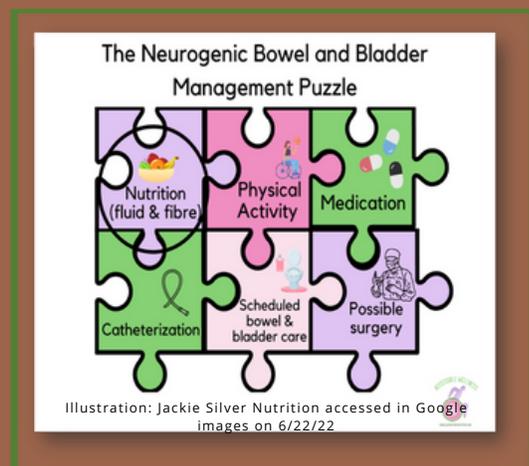
A final recommendation for others with SCI comes from a person in our study who has been there:

"Educate yourself. You know, read, Read up on options. Talk to your doctor. Talk with your friends and family, of course. Just think of all the options and weigh the pros and cons. And when you have chosen a course of action, just look for support amongst your healthcare professionals, friends, and family, and (then) go for it."

"...the reason I'm a 10 is because of the learned experiences that I've had to encounter throughout my life. You build confidence. So, as you age with SCI, you become more confident in your ability to manage. You know, you find what worked and what hasn't worked, and the number one issue I would say is people should always consult with their PMR doctors."

BOTTOM LINE:

To achieve the outcomes you ultimately hope for, you must become your own best researcher.



A Word from

the Project Research Team to our Participants

Thank you for giving so much to others by sharing your thoughts, concerns and impressions with us during this study.

Please watch for our next newsletter coming in October!

Editors:
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