

Thinking It Through

What's Best for You?

How do you deal with complications related to your bladder and bowel after spinal cord injury (SCI)? What are the best options for you? Making the right decisions is not an easy process.

Our first newsletter of this series dealt with factors influencing these decisions, such as type of changes required to address these health complications, cost of procedures and treatment, advice and guidance from doctors and family, access to good health care facilities, and how your decisions will impact your quality of life.

This, our second issue, focuses on how to go about making these decisions, what resources to use, what steps to take, with whom to speak, how to evaluate everything, and how to act in order to get the right results.

Read on to discover articles about the process of decision making itself; and an interview with a man who has lived many years with SCI and is an experienced peer counselor. You will also see some new data from our study, and resources for you on this topic.

DECISION MAKING ABOUT SCI

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

How to Decide?

Understanding the Mechanisms of Decision Making from the Patient's Perspective

By: Denise G Tate PhD, Professor of Physical Medicine and Rehabilitation (PMR), University of Michigan (U-M) and Project Director

Current decision making practices have often led to inadequacies in the medical treatment of bowel and bladder complications. Our research asserts that enhancing patients' involvement in decision making may improve the appropriate use of interventions. The goal is to promote patient autonomy and ability to manage his/her own care.

The process of decision making involves one's abilities and coping styles, information exchange, education, and a dynamic relationship between the patient and his/her doctor. The interplay of these factors contributes to the person's sense of self-efficacy and actual ability to put their decisions into practice. New choices need to be made regarding bladder or bowel conditions requiring surgery, changes in medications and diagnostic procedures that can trigger serious and stressful events.



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

The impact of these decisions on one's life cannot be minimized when we consider what can go wrong. In our study, for example, we learned about both the positive and negative ways participants responded to having a colostomy.

Below is a quote by a participant who experienced very painful hemorrhoids and constipation and developed high blood pressure. He had a hard time with the selected procedure and did not have a good relationship with his doctor.

"And then gosh, it's a nightmare. And then, that just inflamed my hemorrhoids to the point where yeah, my blood pressure was like 290. I was literally gonna die so they had to go in and they gave me a colostomy bag. So, I had it for six years. So that's a whole 'nother thing to get used to. Ugh! So, you get, you get mucus drainage. Yeah, why didn't you guys tell me that?"

Another participant who previously worked as an EMT, had repeated issues with non-healing pressure sores and started to have too many bowel accidents. He, too, got a colostomy.

"I've taken care of people with colostomies in the past, years ago. They said, if you want to get these wounds healed, that's the way to go. I still took two weeks to finally say yes (to colostomy) ...Well, I can do pretty much anything I want to do...You know, it's just a matter of planning and doing it..."

These decisions are not easy to make because the thought of unanticipated problems can be quite frightening. Medical decisions about conditions such as those related to bladder and bowel must be made, and they are often made under conditions of uncertainty, generating undue stress for the person having to make them and for their families, as well.

Most people are not knowledgeable enough to make such important decisions quickly. Seeking guidance from experts becomes critical. It's also essential to do some soul searching about your ability to live with the level of uncertainty about these decisions and how they may impact relationships, activities, and life in general.

Our study participants recommended strategies they use to remove some of that uncertainty from their process of decision making. Their advice follows:

- 1) Talk to your doctor or to a clinical provider that you trust and respect**
- 2) Talk to peers and family or friends who may understand the risks and benefits of these decisions**
- 3) Do some web searches for information on the topic you are interested in, such as colostomies, but make sure you are on a secure and reliable site**
- 4) If you know someone who had the procedure or received the treatment, go talk to them.**

My Body, My Choice: A Candid Chat with Tom Hoatlin

Interviewed by: Denise G. Tate, PhD



Tom enjoys introducing his favorite furry friend to his new number one granddaughter

Having to make decisions about one's healthcare is a major issue for any of us as these can be complex and difficult to figure out. It is especially challenging if these decisions affect one's sense of independence and could possibly change relationships with family, friends and co-workers. In many cases, having to make decisions related to bladder and/or bowel complications after SCI can involve a great degree of uncertainty since best treatment evidence may not be available yet. We are interested in knowing how a person with SCI makes such decisions on a daily basis. Tom Hoatlin, well-respected professional in the field of disability, agreed to share his life experience with us.

Interviewer: What has been your personal experience making decisions related to bladder or bowel complications? What strategies have you used?

Tom: To the general population, making decisions in your life can be a quick check and balance as it doesn't always require much thought. In contrast, when you look at people with SCI, the decision making process can be much more complex, life-changing, and unprecedented.

I have made decisions regarding my bowel and bladder many times in the 30 years since my life changed-- permanently. While managing a suburban

hotel, in 1981, I sustained a T2 (complete) spinal cord injury when I was shot during a robbery. What I did not know at the time was that I would never go to the bathroom the way I had for 25+ years.

The decisions I have had to make for bladder management have ranged from a bladder augmentation to regularly scheduled Botox injections to prevent leaking between catheterizations. The bowel decisions have been the hardest, most complex and would change everything I knew about having bowel movements. In 1996 I developed a very large pressure sore. The doctors told me the only way to heal from this type, location

What I See is What I Get

From the patient's perspective, two psychological concepts are critically intertwined in enacting difficult decisions: cognitive appraisal and coping. By using cognitive appraisal, a person categorizes an encounter (e.g. episodes of bladder leakage) and its facets with respect to its significance for personal and social well-being. It is largely evaluative, focused on meaning-making.

The concept of **cognitive appraisal** is deeply entrenched in the research and theory on stress and coping by Lazarus and Folkman. Many participants appraised their situation, for example bladder leakage, as a challenge or something that can be overcome, while others saw it as a threat, being overwhelmed by it and responding to the problem with anger, irritation, fear, and resentment. A few saw their health circumstances as a loss, suggesting permanent functional or emotional losses in their lives.

Here is what someone said about being overwhelmed:

"There's so many other things going on and I think you have to kind of pick and chose your battles at the time. That's me you know, instead of dealing with 50 things all at once... Well, let's do your bowel program. We'll do this. We'll work on therapy. We're gonna get your bladder going. It just became too overwhelming."

To put a decision into action becomes easier if you can see it as something to be overcome. A plan can be made with gradual steps to get to the final goal of stopping and minimizing the problem and its consequences for lifestyle. Being overwhelmed is not a good way of coping with these stressful events.

Coping requires constantly changing cognitive and behavioral efforts to manage the specific demands that are viewed as taxing or exceeding one's personal resources to manage the problem.

Trying to find positive ways of managing the problem is highly recommended.

In our study we looked at two types of coping with bladder and bowel problems: *problem focused coping*, a process directed at initiating direct action to address stressful situations and *emotion focused coping*, a process directed at managing emotional responses such as fear and anger to address these situations. Both can occur simultaneously.

The first type of coping includes steps like defining the problem, generating alternative solutions, weighing options in terms of costs and benefits, choosing among them, and acting. The second type of coping includes tactics like avoidance (delaying a response to the problem, for example); distancing from the problem by not talking about it, or distancing from others who can help; minimization ('oh well, it's not so bad') and reappraisal of the situation in either a more positive or negative way. These two forms of coping often operate together and complement each other. They can have negative consequences, but they can also provide a healthy path to address these complications:

"Because it's not so bad...I like the work I'm doing. I like...the people that I know and my friends and my family and I like, you know, I like some of the things I got going on."

Finding meaning in life events and situations through spirituality is also a way of coping effectively with the difficult problems related to bowel and bladder, like recurrent urinary tract infections (UTIs), constipation, hemorrhoids:

"For me, I asked the Big Man Upstairs to, you know, help me out here as far as take it away, but it's part of life that I have to bear. That's all. And to me it's... He'll help me with the strength to get through it. So, that's where my faith comes in."



Study Findings: Differences and Similarities Between Veterans and Civilians with SCI

Our study team interviewed an equal number of veterans and civilians with SCI. When individuals whom we interviewed reflected upon their current health care challenges, the use of cognitive appraisal to make decisions was reported equally by veterans and civilians. Cognitive appraisal as a strategy in decision making added a dimension of finding and attributing meaning in relation to themselves:

"...more convenient for me and works better for me".

Study participants used certain emotional coping strategies to deal with the impact of stressful decisions. These included expressing their need for emotional support, talking about fear, shame, and loneliness. They often practiced avoidance behaviors as well. Expressing their spirituality was another important coping strategy. As with cognitive appraisal, an almost equal number of veterans and civilians used emotional coping strategies in decision making.

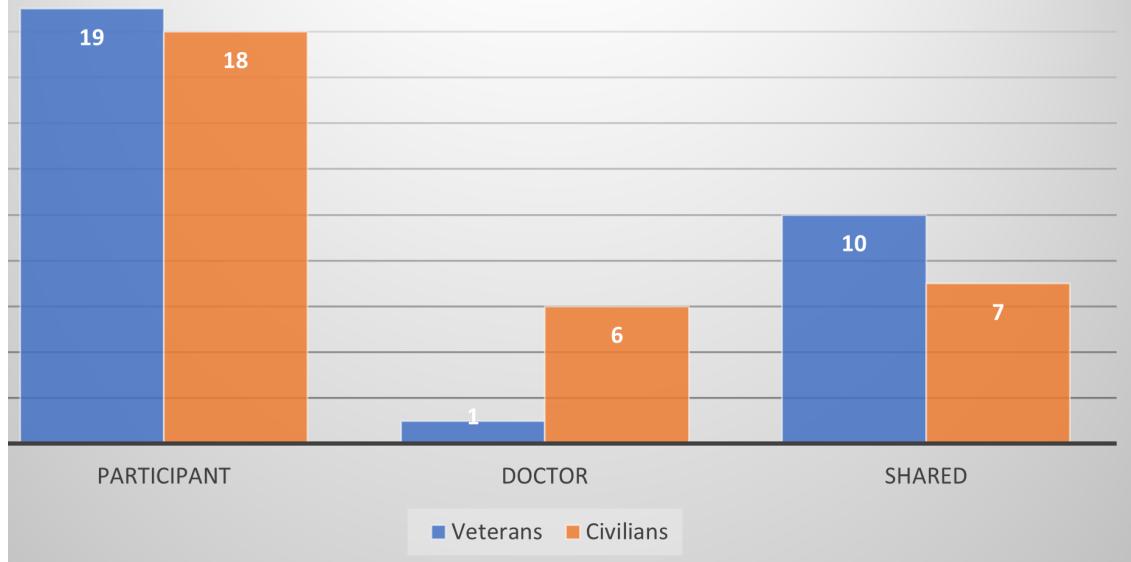
About 40% of all participants told us about their emotions in relation to having to make decisions, thus revealing the high level of complexity involved in the process, along with fear of possible negative consequences:

"This is one of those times where I felt like it was my call. I decided it and I was on top of it for once. I was, you know, thinking of my care and what needed and not just, Oh I don't want to deal with it. Or I'll just keep doing this way. It was a, 'No, I need to deal with this. No, this, needs to be handled.' You know, quit procrastinating and it needs to get done. You need to stop worrying about having these accidents. You need to stop worrying the people around you or taking them out of their lives and what they were doing so they can handle you when there are better ways out there."

In general, decisions about bladder management were associated with self-perception of skills, abilities, being resourceful and decisive, and using challenge as a cognitive appraisal strategy. Decisions about bowel management were more associated with the need for social support. Most participants (75%) used challenge as their preferred way of viewing their problems, with only 23% interpreting their situations as threats.

When having to make bladder decisions, most veterans and civilians perceived their problems as challenges. In contrast, most civilians with SCI, viewed their bowel decisions as threatening and felt overwhelmed by them, while most veterans (77%) saw them as challenges. The veterans in this study were older than the civilians, but both groups averaged over 20 years since injury.

Who Makes the Decision?



Our participants with SCI, both veterans and civilians, were asked during their interviews, *who made the final decision about their bladder or bowel problems?*

Upon reflection, **the majority disclosed that they had the final say about what to do to address their problem.**

More civilians talked to their doctors than veterans, but more veterans shared their decision making with others: doctors, family, friends, caregivers, and other providers. (See graph.)

**Tom shares a dance
with his daughter at her
wedding**



and pressure sore size was to have a temporary reversible colostomy as they were afraid the sore could track into my colon, and I may not have survived that kind of infection. I reluctantly agreed to the surgery. It took a year to heal that massive sore but now I could get the colostomy reversed. Or did I really want to? By the time the sore healed, I had gotten used to the ease and independence that the colostomy afforded me. Bowel programs took five minutes versus two to three hours as they had before the surgery. I could even travel on my own and no more bowel accidents! That colostomy, in essence, saved my life because the sore has vanished.

Interviewer: Were you happy with your decisions? What changes would you make if you had to make a similar choices again, considering bowel accidents or bladder incontinence? Was your doctor helpful in finding the right solution and assisting you with this decision?

Tom: The strategy that has worked for me is *due diligent research* starting with my physician FIRST. Then I discuss the topic with family and friends. Their advice, though, tends to be more of an opinion/guess, based on how much information I initially share with them.

The next stage is to ask peers with SCI that have actually been through this decision making and can offer firsthand knowledge on their experience. All I heard was that it had changed their lives and they had never looked back!

Me either! During the 30 years of having a neurogenic bladder there have been stages of bladder incontinence. I had a bladder augmentation, and many rounds of Botox injections to deaden the valve that wasn't doing its job. I also took many incontinence medications.

At its worst, I was leaking every day for months at a time. Terrible quality of life. I wanted to stay home so I didn't leak and smell like urine. I became depressed and thought this was my future life--stuck forever with typical SCI bladder issues.

Fast forward to today. My bladder behaves in an exemplary way with very few complications or leaking. And, yes, I am still happy with my decision to have the "temporary-turned-permanent" colostomy.

My doctors were integral contributors to make this life-altering surgery but the most valuable participant in this decision making was me. I made it on my own terms. **My body, my choice.**

Getting to Know Your Own Body: Consumer Guides from the Paralyzed Veterans of America (PVA)

Participants in our study seemed to have a very good understanding of their body and complications related to bladder and bowel. They spoke about ways of addressing their specific problems based on their own knowledge, doctor's recommendations and by talking to others with similar problems:

"I was a nationally certified pharmacy technician...but just prior experience, (my) knowledge of insurance companies told me that if you keep bugging them and talk to the right person, you're gonna get what you want".

Both civilians and veterans with SCI agreed that bladder complications often required self-awareness skills--to be able to do self-care, have self-discipline, and be skilled in methods of management.

For those with less experience and knowledge, PVA offers many resources for persons with SCI/D, and for their families and others who wish to learn more about their own bodies. The Consortium of Spinal Cord Medicine has prepared clinical practice guidelines for bladder management and neurogenic bowel for professionals responsible for patient care. Consumer guides are also available by going to <https://pva.org/research-resources/publications/consumer-guides/>. Check out these great resources:

- ✓ *Neurogenic Bowel: What You Should Know* and
- ✓ *Bladder Management following Spinal Cord Injury: What You Should Know.*

You can download these for free from the PVA website.



Share Your Concerns About Bladder and Bowel Care with Your Doctor

Several of our study participants talked about making decisions in consultation with their doctors. A 29-year-old participant with UTIs says:

"You definitely want to talk to your doctors and your urologist when it comes to UTIs and stuff like that."

Sharing your concerns and thoughts can be most helpful.

Dr. Gianna Rodriguez is the Spinal Cord Injury Director, Medical Director of the Wheelchair Seating Clinic, the Lead in the Michigan Bowel Control Clinic and the Wound Care Clinic in the Department of Physical Medicine and Rehabilitation at the University of Michigan. She also serves as the Co-Investigator of the newly funded Spinal Cord Injury Model System. When asked about what advice she would give to her patients with spinal cord injury and disorders who are having trouble making decisions about their bladder and/or bowel care, she explained that talking to your doctor is the best thing you can do to prevent complications.



"Your medical health care professional will be providing you with education from the scientific and experiential standpoints and will answer your questions throughout the course of your lifetime; with every intention to prevent medical complications and hospital admissions, keep you healthy, and preserve good quality of life. Working closely with your medical provider will allow you to make the most appropriate decisions for yourself as you balance your priorities in life."

--Gianna Rodriguez, M.D.

Bottom Line:

Do you have a game plan for managing new bowel and bladder complications? How will you decide what's right for you?

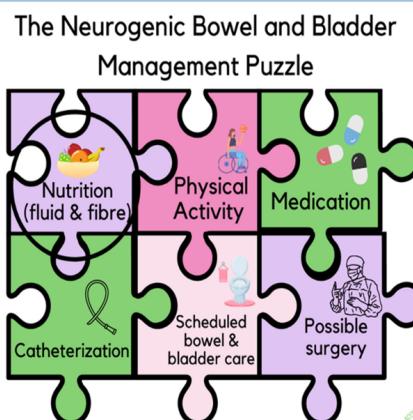


Illustration: Jackie Silver Nutrition accessed in Google images on 6/22/22

Different Ways to Make Important Health Care Decisions: Where Do You See Yourself?

According to Maibach et. al,* there are several ways that people make decisions about their health care issues. Basically, the process of deciding depends on one's personal perspective about power and capability—their own and their doctor's. The Maibach group describes four kinds of decision-makers:

1. Independent Actives who:
 - a. Value health information and believe in prevention, their own good judgement, and their doctor's reliability
 - b. Collaborate with their doctor, but **make their own final decisions**
2. Doctor-dependent Actives who:
 - a. Believe health information is important but find it hard to understand
 - b. Collaborate with their doctor and **give the doctor final decision making power**
3. Independent Passives who:
 - a. Are not very interested in prevention and don't partner with their doctor when making big decisions
 - b. **Make the final decisions on their own**
4. Doctor-dependent Passives who:
 - a. Are not very interested in prevention and health information and often don't understand it
 - b. Don't collaborate with their doctor much and **give the doctor full authority to make the big decisions** for them.

In our U-M study, 10 participants completed a questionnaire that the Maibach group created to decipher people's health information and decision making preferences. 100% of our sample was likely to be engaged in health information and prevention efforts. 67% leave the final decision up to their doctor, although they do collaborate with him/her. One third of the 10 people ultimately make final health decisions themselves after they collaborate with their doctor.

What's your decision making style? Which group do you relate to the most? Does your decision making style work well for you?

*Reference article: Maibach, E. W., Weber, D., Massett, H., Hancock, G. R., & Price, S. (2006). Understanding consumers' health information preferences: development and validation of a brief screening instrument. Journal of health communication, 11(8), 717-736. <https://doi.org/10.1080/10810730600934633>

Editors:
Denise G.Tate
Sunny Roller

Watch for the next newsletter coming in September!