SFU SIMON FRASER UNIVERSITY
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Cover page for paper-based questionnaire

Bowel care and cardiovascular function after spinal cord injury

Introduction and Purpose: You are invited to participate in a survey about bowel care and cardiovascular function after spinal cord injury (SCI) by Dr. Victoria Claydon, and her student Jessica Inskip, from Simon Fraser University, Burnaby, BC, Canada.

Bowel care has been identified as a key aspect for improving quality of life for individuals living with SCI. However, it has become clear that we do not know very much about current bowel care practices. We are hoping to gather more details about individuals' current bowel care practices and their cardiovascular responses to bowel care.

Individuals living with SCI everyday are the experts in this area. Your contribution to this research may help inform future individuals who sustain a SCI by describing practices currently used by individuals living with SCI. For example, it will help provide clearer explanations of bowel care practices for information manuals. Finally, it will also help to direct future research and improvements in care.

Voluntary: Your participation in the survey is completely voluntary and you are under no obligation to participate. There will be no consequence for you if you are not interested in taking part in the survey.

If you do not want to answer some of the questions you are free to skip them and complete what you feel comfortable with. If you complete the survey this will mean that you have consented to participate in this project and that the research team is able to include your responses to the survey questions in the data collection.

Confidentiality: These surveys will be anonymous in nature. There will be no identifying information (i.e. date of birth, name) collected from participants. All data collected will be stored securely in Dr. Claydon's research office, and only research staff will have access to this information. If you have any questions or concerns, you can contact Dr. Victoria Claydon at victoria_claydon@sfu.ca or by phone at 1-778-858-8118; or Hal Weinberg, Director of the Office of Research Ethics at Simon Fraser University (E-mail: hal_weinberg@sfu.ca; phone: 1-778-7782-6593).

Copies of the results can be obtained by contacting the investigators at the number above or in writing to Jessica Inskip at jinskip@sfu.ca.

Before completing the survey: I have read the information about this study and would like to complete the survey now. By completing and returning the survey, I am confirming that I **have a spinal cord injury and am over the age of 18**.

SFU SIMON FRASER UNIVERSITY
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Cover page for online questionnaire

Bowel care and cardiovascular function after spinal cord injury

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Before completing the survey: I have read the information about this study and would like to complete the survey now. By clicking on the "**Next**" button below, I am confirming that I **have a spinal cord injury and am over the age of 18**. If I start the survey and decide I don't want to finish it I can exit the survey at any time.

BOWEL CARE AND CARDIOVASCULAR FUNCTION AFTER SPINAL CORD INJURY

Identification Number _____ Date completed DD/MM/YYYY

Date of Birth DD/MM/YYYY Date of Injury DD/MM/YYYY

PATIENT INFORMATION/DEMOGRAPHICS

1. **What site on your spinal cord is injured?**

   _____

2. **Can you feel touch in your anal area?**
   ☐ Yes ☐ No

3. **Can you voluntarily tighten your anal sphincter?**
   ☐ Yes ☐ No

4. **Can you feel light touch below your lesion level?**
   ☐ Yes ☐ No

5. **Can you feel the difference between sharp and dull below your lesion level?**
   ☐ Yes ☐ No

6. **Can you lift your legs against gravity?**
   ☐ Yes ☐ No

7. **Can you walk without braces, other assistive devices, or people?**
   ☐ Yes ☐ No

8. **What assistive devices do you use most often in your daily life?**
   ☐ None
   ☐ Cane
   ☐ Crutches
   ☐ Manual wheelchair
   ☐ Motorized wheelchair
   ☐ Other. Please specify: _____

BOWEL CARE QUESTIONS

9. **Are you satisfied with your bowel management routine?**
   ☐ Yes, very satisfied
   ☐ Yes, satisfied
   ☐ No, dissatisfied
   ☐ No, very dissatisfied

10. What steps do you use to empty your bowel? Check all that you use:

	Main	Supplementary
Normal defecation/straining/bearing down	☐	☐
Drink/food before bowel management	☐	☐
Massaging or rubbing abdomen	☐	☐
Touching the skin around the anus	☐	☐
Digital stimulation	☐	☐
Manual evacuation	☐	☐
Suppositories	☐	☐
Laxatives	☐	☐
Enemas	☐	☐
Stool softeners	☐	☐
Other, please specify; _____	☐	☐

11. How long have you been managing your bowel routine this way?

☐ Less than 6 months
☐ Less than one year (between 6 months and 1 year)
☐ Up to 5 years (between 1 year and 5 years)
☐ Longer than 5 years

12. Do you currently use lidocaine lubricant (an anesthetic, also called Xylocaine) as part of your bowel care management routine?

☐ No, never
☐ Yes, sometimes
☐ Yes, always
☐ I don't know

13. How often do you perform your bowel care?

☐ Three times or more per day
☐ Twice daily
☐ Once daily
☐ Not daily but more than twice every week
☐ Twice every week
☐ Once every week
☐ Less than once every week, but at least once within the last four weeks

14. How are you normally positioned during your bowel care?

☐ Sitting on toilet chair/commode
☐ Sitting on a raised toilet seat
☐ Lying in Bed
☐ Other, please specify:_____

15. How much do you usually drink each day?
- ☐ ½ litre (about ½ quart)
- ☐ 1 litre (about 1 quart)
- ☐ 1-2 litres
- ☐ More than 2 litres

16. Do you take any other medications that might affect bowel function?
- ☐ No
- ☐ Not sure
- ☐ Yes, anticholinergics (Ditropan/LyrineIXL Vesicare, Detrol, Toviaz)
- ☐ Yes, opiates (methadone, codeine, etc.)
- ☐ Yes, antidepressants (Tricyclics: Elavil, Amitriptyline, Nortipyline, Desipramine)
- ☐ Yes, other. Please specify: _____

17. Do you regulate your diet to help with bowel management? (For example, by taking fiber supplements or eating certain fiber-rich foods?)
- ☐ No
- ☐ Yes. Please explain: _____

18. Do you require assistance to perform your bowel care?
- ☐ Required total assistance
- ☐ Required partial assistance; did not clean self
- ☐ Required partial assistance; cleaned self independently
- ☐ Performed care routine independently in all tasks but needed adaptive devices or special setting (e.g., bars)
- ☐ Performed care routine independently; did not need adaptive devices or special setting

19. What is the average time that you require for bowel care?
- ☐ 0-5 min
- ☐ 6-10 min
- ☐ 11-20 min
- ☐ 21-30 min
- ☐ 31-60 min
- ☐ 61-90 min
- ☐ More than 90 min
- ☐ Unknown

20. Breaking down the events and intervals of defecation:

a. Average time from initiation of bowel care to the time that stool comes out:
- ☐ Minutes: _____
- ☐ Not Applicable
- ☐ Unknown

b. **Average time during bowel care movement that stool intermittently or continuously comes out with or without assistance:**
☐ Minutes: _____
☐ Not Applicable
☐ Unknown

c. **Average time spent waiting after last stool passes before ending bowel care:**
☐ Minutes: _____
☐ Not Applicable
☐ Unknown

21. **At what time do you usually do your bowel care?**
☐ Morning
☐ Evening
☐ Other: _____

22. **How flexible is your bowel management routine?**
☐ Very flexible – I often change the time or frequency at which I manage my bowels
☐ Quite flexible – I can delay management or alter the timing if I want to
☐ Not very flexible – I don't usually change my routine unless it's unavoidable
☐ Not flexible at all – I will not go to activities if they clash with my bowel management time

23. **Do you wear a pad or plug to manage bowel accidents?**
☐ Everyday
☐ Not every day but at least once per week
☐ Not every week but at least once per month
☐ Less than once per month
☐ Never

24. **How are you aware of the need to defecate?**
☐ Direct sensation
☐ Indirect sensation (e.g., abdominal cramping or discomfort, abdominal muscle spasm, spasm of lower extremities, perspiration, headache, chills)
☐ None
☐ Unknown

25. **How often do you experience pain during bowel care?**
☐ Daily
☐ Not every day but at least once per week
☐ Not every week but at least once per month
☐ Less than once per month
☐ Never
☐ Unknown

26. How often do you experience abdominal bloating or discomfort (ANYTIME – not only during bowel care)?

☐ Daily
☐ Not every day but at least once per week
☐ Not every week but at least once per month
☐ Less than once per month
☐ Never
☐ Unknown

27. How often do you experience respiratory discomfort (shortness of breath/difficulty in taking a deep breath) due in part to a distended abdomen?

☐ Daily
☐ Not every day but at least once per week
☐ Not every week but at least once per month
☐ Less than once per month
☐ Never
☐ Unknown

28. If you had to estimate your frequency of fecal incontinence:

☐ Two episodes or more per day
☐ Once daily
☐ Not every day but at least once per week
☐ Not every week but at least once per month
☐ Once per month
☐ Less than once per month
☐ Never
☐ Not applicable
☐ Unknown

29. Does fecal incontinence alter your lifestyle?

☐ Lifestyle altered each day
☐ Lifestyle altered at least once per week but not every day
☐ Lifestyle altered more than once per month but not every week
☐ Lifestyle altered once per month
☐ Lifestyle altered less than once per month
☐ Lifestyle not altered
☐ Not applicable
☐ Unknown

30. What is the overall impact of bowel dysfunction on your quality of life?

☐ Major impact
☐ Some impact
☐ Little impact
☐ No impact

31. How does bowel management fit into your life? Please check one box beside each statement:

	Not at all	A little	A lot
I fit my life around my bowel management	☐	☐	☐
Bowel management stops me from working outside my home	☐	☐	☐
Managing my bowels interferes with personal relationships	☐	☐	☐
Bowel management stops me staying away from home	☐	☐	☐
My bowel management is a problem to me	☐	☐	☐
Bowel management interferes with my social life	☐	☐	☐

32. How much does bowel management affect your life compared to other aspects of spinal cord injury?
Please give each of the following a score between 1 and 10, where 10 is the worst effect and 1 is the least.

Managing my my bladder: _____ ☐ Does not apply
Changes in my sexual function: _____ ☐ Does not apply
Using a wheelchair: _____ ☐ Does not apply
Taking care of my skin: _____ ☐ Does not apply
Managing my bowel: _____ ☐ Does not apply
Living with chronic pain: _____ ☐ Does not apply
Living with spasticity: _____ ☐ Does not apply

CARDIOVASCULAR QUESTIONS

33. During your bowel routine, do you ever experience any heart palpitations, irregular heartbeats or a feeling of "fluttering" in your chest?
☐ Yes ☐ No

34. If yes, how often do you normally experience this?
☐ Daily
☐ Weekly
☐ Monthly
☐ Rarely
☐ Never

35. How would you rate the following symptoms during your normal bowel routine?

	Not experienced	Mild	Moderate	Severe	Very severe
Headache	☐	☐	☐	☐	☐
Dizziness	☐	☐	☐	☐	☐
Nasal congestion	☐	☐	☐	☐	☐
Goosebumps	☐	☐	☐	☐	☐
Blurred vision/visual sensitivity	☐	☐	☐	☐	☐
Visual tunneling	☐	☐	☐	☐	☐
Facial flushing	☐	☐	☐	☐	☐
Profuse sweating	☐	☐	☐	☐	☐
Difficulty breathing	☐	☐	☐	☐	☐
Spasticity	☐	☐	☐	☐	☐
Nausea	☐	☐	☐	☐	☐
Shortness of breath/chest tightness	☐	☐	☐	☐	☐
Chest pain	☐	☐	☐	☐	☐
Palpitation	☐	☐	☐	☐	☐
Uncomfortably fast heart rate	☐	☐	☐	☐	☐
Uncomfortably slow heart rate	☐	☐	☐	☐	☐
General unwellness	☐	☐	☐	☐	☐
Seizure	☐	☐	☐	☐	☐
Pain	☐	☐	☐	☐	☐
Other, please specify; _____	☐	☐	☐	☐	☐

AUTONOMIC DYSREFLEXIA QUESTIONS

Autonomic dysreflexia refers to increases in blood pressure that occur in response to a sensory stimulus below the level of spinal cord injury. The sensory stimulus may be something that would normally be expected to be painful (e.g., a bump) or non-painful (e.g., a full bladder). The stimulus does not need to be perceived to cause autonomic dysreflexia.

36. Have you ever experienced autonomic dysreflexia since your injury?

☐ Yes
☐ No
☐ Don't know

37. If yes, how many times?

☐ Once only
☐ 1-3 times
☐ 4-7 times
☐ More than 8 times

38. How often do you experience the following symptoms?

	Daily	Weekly	Monthly	Rarely	Never
Headache	☐	☐	☐	☐	☐
Dizziness	☐	☐	☐	☐	☐
Nasal congestion	☐	☐	☐	☐	☐
Goosebumps	☐	☐	☐	☐	☐
Blurred vision/visual sensitivity	☐	☐	☐	☐	☐
Visual tunneling	☐	☐	☐	☐	☐
Facial flushing	☐	☐	☐	☐	☐
Profuse sweating	☐	☐	☐	☐	☐
Difficulty breathing	☐	☐	☐	☐	☐
Spasticity	☐	☐	☐	☐	☐
Nausea	☐	☐	☐	☐	☐
Shortness of breath/chest tightness	☐	☐	☐	☐	☐
Chest pain	☐	☐	☐	☐	☐
Palpitation	☐	☐	☐	☐	☐
Uncomfortably fast heart rate	☐	☐	☐	☐	☐
Uncomfortably slow heart rate	☐	☐	☐	☐	☐
General unwellness	☐	☐	☐	☐	☐
Seizure	☐	☐	☐	☐	☐
Pain	☐	☐	☐	☐	☐
Other, please specify; _____	☐	☐	☐	☐	☐

39. What sorts of things trigger these symptoms?

	Yes	No	Not applicable
Bladder trigger	☐	☐	☐
Bowel trigger	☐	☐	☐
Sexual activity	☐	☐	☐
Pain	☐	☐	☐
Pressure sores	☐	☐	☐
Spasticity	☐	☐	☐
Ingrown nails	☐	☐	☐
Fracture	☐	☐	☐
Tight clothes/devices	☐	☐	☐
Menstrual cramps	☐	☐	☐
High/low temperatures	☐	☐	☐
Blood clot	☐	☐	☐
Other, please specify; _____	☐	☐	☐

40. Has autonomic dysreflexia every interfered with your ability to participate in the following activities?

	Yes	No	Not applicable
Activities of daily living	☐	☐	☐
Work	☐	☐	☐
Exercise	☐	☐	☐
Sexual activity	☐	☐	☐
Rehabilitation	☐	☐	☐
Household chores	☐	☐	☐
Driving	☐	☐	☐
Social activities	☐	☐	☐
Sleep	☐	☐	☐
Other, please specify; _____	☐	☐	☐

41. Have you ever used autonomic dysreflexia to boost your sports performance?
- ☐ Yes
- ☐ No
- ☐ Not applicable
- ☐ Prefer not to answer

ORTHOSTATIC HYPOTENSION QUESTIONS

42. Have you ever fainted prior to your injury?
- ☐ Yes
- ☐ No
- ☐ Don't know

43. If yes, how many times?
- ☐ Once only
- ☐ 1-3 times
- ☐ 4-7 times
- ☐ More than 8 times

44. Have you ever fainted since your injury?
- ☐ Yes
- ☐ No
- ☐ Don't know

45. If yes, how many times?
- ☐ Once only
- ☐ 1-3 times
- ☐ 4-7 times
- ☐ More than 8 times

46. How often do you experience the following symptoms WHEN UPRIGHT (and NOT while experiencing autonomic dysreflexia)?

	Daily	Weekly	Monthly	Rarely	Never
Dizziness	☐	☐	☐	☐	☐
Fainting/Blackouts	☐	☐	☐	☐	☐
Lightheadedness	☐	☐	☐	☐	☐
Blurred vision	☐	☐	☐	☐	☐
Visual tunneling	☐	☐	☐	☐	☐
Profuse sweating	☐	☐	☐	☐	☐
Profound tiredness/lethargy	☐	☐	☐	☐	☐
Spasticity	☐	☐	☐	☐	☐
Nausea	☐	☐	☐	☐	☐
Shortness of breath	☐	☐	☐	☐	☐
Palpitations	☐	☐	☐	☐	☐
Uncomfortable fast heart rate	☐	☐	☐	☐	☐
Uncomfortable slow heart rate	☐	☐	☐	☐	☐
Extreme pallor	☐	☐	☐	☐	☐
Seizure	☐	☐	☐	☐	☐
Other, please specify; _____	☐	☐	☐	☐	☐

47. What sorts of things trigger these symptoms?

	Yes	No	Not applicable
Bladder trigger	☐	☐	☐
Postural change in the morning	☐	☐	☐
Sitting still in a wheelchair	☐	☐	☐
Being in a warm room	☐	☐	☐
Drinking alcohol	☐	☐	☐
Stopping exercise	☐	☐	☐
After meals	☐	☐	☐
After bathing	☐	☐	☐
Blood sampling/ sight of blood	☐	☐	☐
Physiotherapy	☐	☐	☐
Other, please specify; _____	☐	☐	☐

48. Has orthostatic hypotension interfered with your ability to participate in the following activities?

	Yes	No	Not applicable
Activities of daily living	☐	☐	☐
Work	☐	☐	☐
Exercise	☐	☐	☐
Sexual activity	☐	☐	☐
Rehabilitation	☐	☐	☐
Household chores	☐	☐	☐
Driving	☐	☐	☐
Social activities	☐	☐	☐
Sleep	☐	☐	☐
Other, please specify; _____	☐	☐	☐

49. Place an "x" on each of the following lines to indicate how you are feeling RIGHT NOW.
I am feeling:

Not at all fatigued _____ Extremely fatigued

Not at all tired _____ Extremely tired

Not at all exhausted _____ Extremely exhausted

50. What is your fluid intake each day?
☐ About 500mL (about ½ quart)
☐ 1 litre (about 1 quart or 34oz.)
☐ 1-2 litres
☐ More than 2 litres

51. How much caffeine do you usually drink each day, on average?
(including coffee, tea, soda)
☐ None
☐ 1 cup/can
☐ 2 cups/cans
☐ 3 cups/cans
☐ 4 cups/cans
☐ 5 or more cups/cans

52. How much alcohol do you usually drink each day, on average?
(1 unit = 12oz (350mL) beer, 5oz (150mL) wine, 1.5oz (44mL) liquor)
☐ None
☐ 1 unit
☐ 2 units
☐ 3 units
☐ 4 or more units

53. If you had to estimate your average daily urine output (24 hours), would it be:
☐ <1000mL
☐ 1000mL
☐ 2000mL
☐ 3000mL
☐ 4000mL
☐ 5000mL or more

54. Do you ever restrict your fluid intake because of bladder control problems or concerns?
☐ No
☐ Yes, but rarely
☐ Yes, sometimes
☐ Yes, often

55. Do you take any diuretics as part of your medications? Diuretics are sometimes called water pills as they increase the amount of urine that you produce (e.g., Lasix, HTCZ, etc.).
☐ No
☐ Yes
☐ Not sure

Thank you very much for taking the time to complete this questionnaire