Autonomic function and spinal cord injury: exploring healthcare provider perspectives on bowel care & reimagining autonomic dysreflexia

by

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Abstract

Spinal cord injury (SCI) can lead to comorbidities that reduce quality of life (QoL), including neurogenic bowel dysfunction and dangerous spikes in blood pressure called autonomic dysreflexia (AD). This thesis aims to contribute to improving the QoL of individuals with SCI. Most individuals with SCI are dissatisfied with their bowel care, but despite dissatisfaction, have not changed it. Chapter 2 presents health care provider barriers and facilitators to conversations about changing bowel care. Several key themes were identified that help or hinder optimising bowel care (knowledge, experience, education and responsibility are needed to have conversations; time and teamwork are valuable yet limited; interpersonal dynamics are present and impactful; beliefs and intentions shape decisions to have conversations). Chapter 3 offers an editorial on the definition of AD; it presents the current definition and considers options for optimisation of AD criteria. Collectively, these chapters contribute to understanding of QoL-limiting problems after SCI.

Keywords: spinal cord injury; autonomic nervous system; quality of life; autonomic dysreflexia; behaviour change science; interviews

Land Acknowledgement

My name is Elin Sober-Williams. I am a settler scholar of British colonizer and Estonian refugee descent. I am a student in the Department of Biomedical Physiology and Kinesiology at Simon Fraser University, on the unceded territories of the xʷməθkʷəy̓əm (Musqueam), Skwxwú7mesh (Squamish), and Səl̓ílwətaʔ/Selilwitulh (Tsleil-Waututh) Nations.

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Positionality Statement

It is important to identify one’s position within their work as there are different levels of validity that come from lived experience (Holmes, 2020). I am a white, cisgender, able-bodied female from an upper-middle class upbringing. I do not have the lived experience of having an SCI or being responsible for the care of someone with an SCI, and as an outsider to the SCI community, my understanding of SCI will always be limited. Due to this limitation I have tried to conduct my work according to the most urgent quality of life-improving areas that individuals with SCI have reported, and have worked in partnership with the SCI community within the Integrated Knowledge Translation guiding principles to ensure this work is relevant and useful to the community. My position as an outsider to the SCI community also carries the potential benefit of reduced bias (Holmes, 2020). Despite my lack of direct personal experience, I am motivated to work in SCI research to contribute to positive changes in quality of life.

Another important consideration regarding positionality is research philosophy. One’s research philosophy influences their epistemology or the ways they evaluate knowledge claims, and depends on their ontology or perception of reality (Abu-Alhaija, 2019; Bolton & Gillett, 2019). There are many different research philosophies, two of which are positivism and pragmatism (Abu-Alhaija, 2019). A positivist is one who believes that quantifiable knowledge gained through observation is “true”, objective, and generalizable (Abu-Alhaija, 2019). A pragmatist is one who is guided to “solve practical problems in the real world”, relying less on assumptions of true knowledge (Maarouf, 2019). I am a pragmatist working in a field that largely operates within a positivist framework. I believe my philosophy makes me well suited to do this work as I understand that each individual holds their own truth, and that by listening to many individuals we can understand common themes between their experiences. Pragmatism is a useful philosophical lens through which to consider mixed-methods research as it can allow for an acceptance of the conflicting assumptions of qualitative and quantitative research (Maarouf, 2019). This philosophy and the surrounding belief that reality is socially constructed allows for reflexivity or awareness, which can help to facilitate acknowledging when research does not contribute to production of helpful knowledge, and work towards bettering future research attempts (Maarouf, 2019; Peat et al., 2019).

Chapter 1. Introduction

1.1. Spinal cord injury is associated with difficulties with blood pressure control and continence management

Spinal cord injury (SCI) not only causes paralysis and loss of sensation, but also damages the autonomic (sympathetic) nerves that control blood pressure and heart rate. This can lead to dangerous blood pressure spikes, known as autonomic dysreflexia (AD), that are triggered by sensations such as a full bladder or bowel. This means that individuals with SCI need to carefully manage their bladder and bowel care to prevent AD.

In addition to these challenges with blood pressure control, individuals with SCI experience a range of continence challenges. In a recent survey, 78% of people with SCI report being dissatisfied with their bowel care routines, ranking functional bowel improvements as among the top priorities for improving QoL (Figure 1) (Anderson, 2004; Inskip et al., 2018). Many people reported that bowel management impacts life activities, and that they have to “fit their life around it” (Figure 2) (Inskip et al., 2018). Despite this dissatisfaction, 71% of individuals have not changed their bowel care routines in at least 5 years (Inskip et al., 2018). We recently surveyed individuals with SCI to identify barriers and facilitators to changing their bowel care (Figure 3). One factor that influenced changing care was knowledge about bowel care options, which highlights the key role of healthcare providers (HCP) in decision-making. However, the factors that influence whether health professionals will recommend or support individuals with SCI to make a change in bowel care are unknown (Lucci et al., 2022).

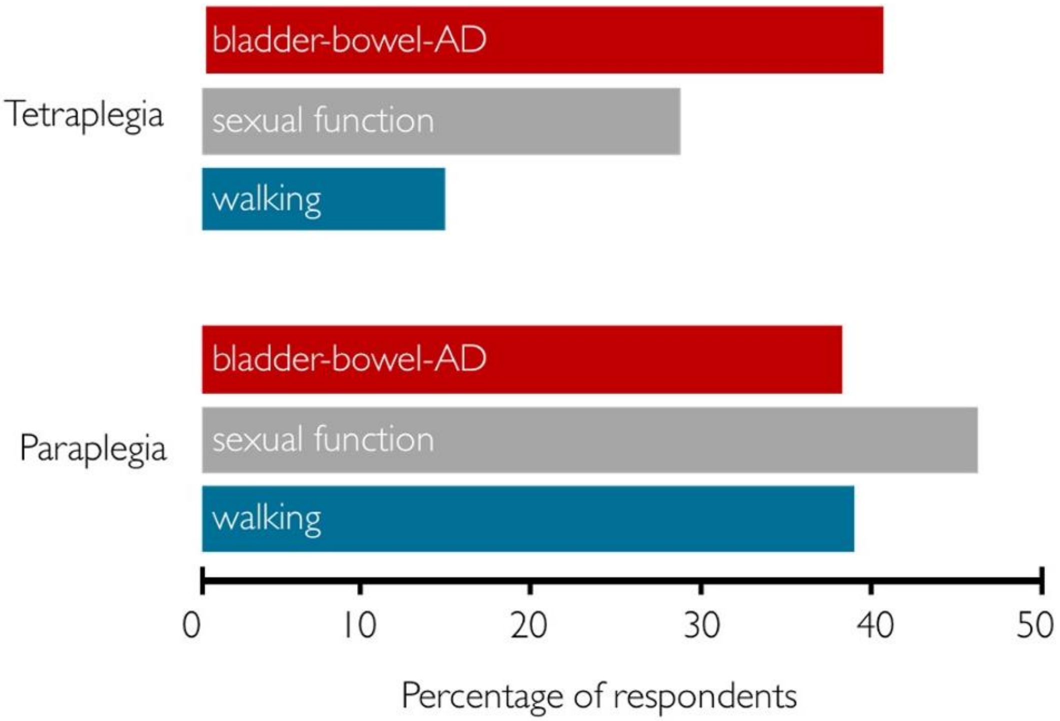


Figure 1. **Areas of functional recovery ranked as most important for improving quality of life of individuals with tetraplegia or paraplegia.**
Adapted from Anderson, K. D. (2004). Targeting recovery: priorities of the spinal cord-injured population. Journal of neurotrauma, 21(10), 1371-1383.

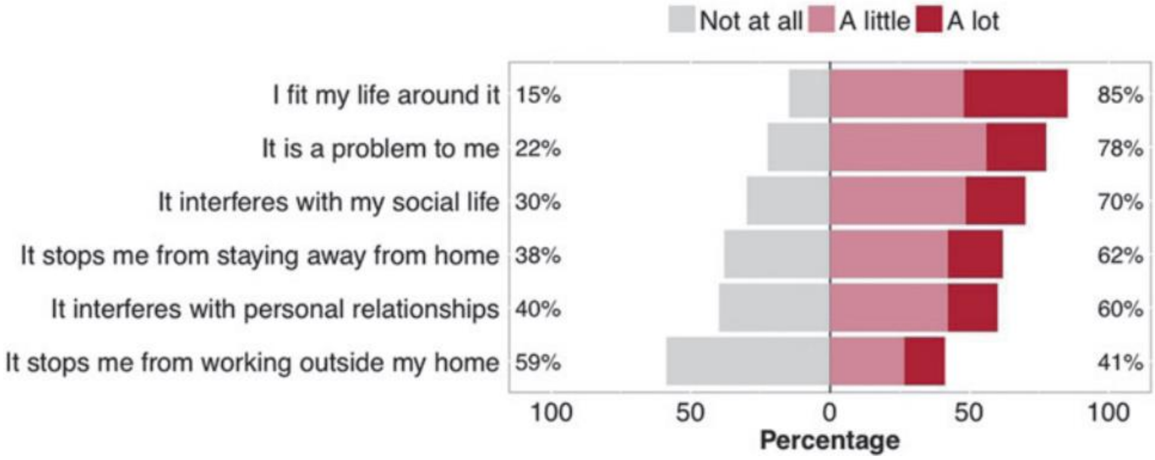


Figure 2. **Impacts of bowel management on life and activities. Bowel care can take substantial time to complete, which impacts lifestyle and limits flexibility and participation in daily life.**
Adapted from Inskip, J. A., Lucci, V. E. M., McGrath, M. S., Willms, R., & Claydon, V. E. (2018). A community perspective on bowel management and quality of life after spinal cord injury: the influence of autonomic dysreflexia. Journal of Neurotrauma, 35(9), 1091-1105.

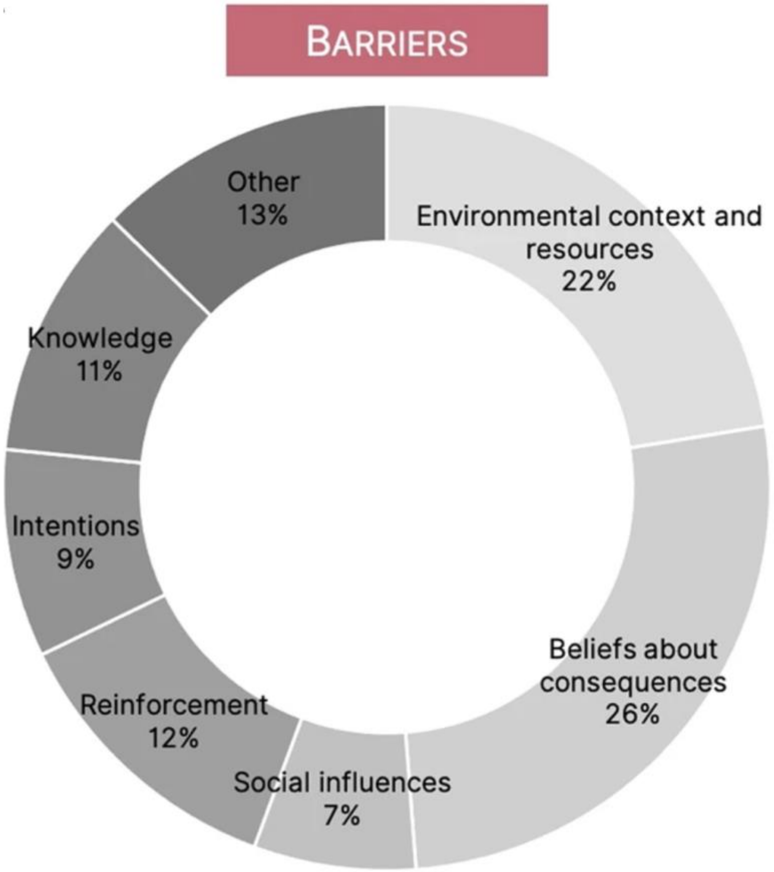


Figure 3. Proportion of barriers to individuals with SCI changing bowel care by TDF domains.
Adapted from Lucci, VE.M., McKay, R.C., McBride, C.B. et al. Barriers and facilitators to changing bowel care practices after spinal cord injury: a Theoretical Domains Framework approach. Spinal Cord 60, 664–673 (2022).

Most importantly, individuals with SCI have identified blood pressure control and continence management as two key target areas for improvement that have the potential to increase their quality of life (Figure 1) (Inskip et al., 2018; Anderson, 2004). The following research aims to investigate the barriers and facilitators to optimising bowel care after SCI from the HCP perspective. Additionally, this thesis will discuss the current definition of AD, hopefully sparking a reconsideration of current diagnostic practices that may improve the utility of the definition for individuals with SCI, clinicians, and researchers. Together, this research will improve the quality of life of individuals with SCI by supporting independence in bowel care and management of AD.

1.2. The impacts of SCI extend far beyond challenges with mobility or sensation

It is estimated that there are over 86,000 people living with SCI in Canada (Praxis Spinal Cord Institute, 2021). While SCI-related deficits in motor and sensory function are well appreciated, the impacts of SCI also extend into numerous other secondary health concerns that further contribute to a reduced life expectancy (Middleton et al., 2012). Some common secondary health concerns stem from broader neurologic dysfunction and include impacts on bladder, bowel, and sexual function, neuropathic pain, and thermoregulation (Figoni et al., 2021). Cardiovascular dysfunction is also common after SCI, causing conditions such as exercise intolerance, arrhythmia, orthostatic hypotension (OH), and AD (Figoni et al., 2021; Partida et al., 2016). Additional secondary health concerns include immunosuppression from catecholamine release, renal dysfunction, and blood vessel remodelling due to shear stress (Elmelund et al., 2016; Phillips et al., 2016; Schwab et al., 2014).

Bowel dysfunction reported in 74.7% (n=2129) of individuals with SCI (M. Coggrave et al., 2009; Craven et al., 2012; Jorgensen S. et al., 2021; Noonan VK et al., 2008; Westgren & Levi, 1998). Bowel dysfunction can occur at any lesion level, but there are patterns of dysfunction according to lesion level. Individuals with injuries above the conus medullaris (neurological lesions at or above T12) may experience upper motor neuron bowel dysfunction (Stiens et al., 1997). Known as a reflexive neurogenic bowel, excessive muscle tone in the colon wall and anal sphincters results in increased colonic transit time and constipation (Rajendran et al., 1992). Individuals with a reflexive bowel are unable to voluntarily relax the anal sphincter and require chemical or mechanical stimuli to trigger reflex defecation (Stiens et al., 1997). Conversely, individuals with lower motor neuron injuries (below T12) typically experience areflexic bowel dysfunction. Due to damage of the parasympathetic pathways distal to the conus medullaris, areflexic bowel dysfunction is characterised by reduced peristalsis, coupled with reduced colonic and sphincter tone. Consequently, individuals with an areflexic bowel experience constipation, but are also at an increased risk of fecal incontinence as the external anal sphincters are relaxed (Stiens et al., 1997).

For individuals with high-level injuries, AD is a cardiovascular complication that often intersects with bowel function. AD describes the phenomenon of profound hypertension secondary to sensory stimuli below the lesion (Cowan et al., 2020; Inskip et al., 2018). The risk for AD is related to the level and severity of injury, with AD occurring in individuals with autonomically severe lesions at or above the level of sympathetic innervation (T6) to the splanchnic vasculature, a critical site for vascular resistance and capacitance responses. The inability to regulate sympathetic outflow to the splanchnic vessels results in impaired autonomic control of blood pressure (Hainsworth & Claydon, 2012). Below the lesion level, sympathetic activity remains unrestrained, and the hypertension will persist until the stimulus is eliminated (Karlsson, 1999). AD typically presents with symptoms of flushing and sweating above the lesion level (in regions under supraspinal control), accompanied by pounding headaches, and sometimes with palpitations precipitated by baroreflex-mediated increases in cardiac parasympathetic drive in response to the hypertension, which may present a stimulus for ‘autonomic conflict’ (Lucci et al., 2021; Shattock & Tipton, 2012). Although AD is often profoundly symptomatic, it can also be ‘silent’, occurring without detectable symptoms, which can be dangerous as the hypertension will persist if there is no attempt to remove the stimulus. In combination with cerebral vasodilation, the high pressures of AD increase the risk of haemorrhagic stroke, and are associated with considerable morbidity and mortality (Allen & Leslie, 2022; Wan & Krassioukov, 2014; C. R. West et al., 2016). It is reported that up to 90% of individuals with tetraplegia or high paraplegia experience AD (Bycroft et al., 2005; Jacob et al., 2005) and susceptible individuals may experience several episodes of AD per day, which can profoundly interfere with activities of daily living and QoL (Carlozzi et al., 2013; M. Coggrave et al., 2009; Inskip et al., 2018). Unfortunately, a distended bowel and bowel management techniques such as digital stimulation are among the most potent visceral stimuli for AD (Bycroft et al., 2005; Faaborg et al., 2014; Furusawa et al., 2011; Karlsson, 1999).

In a survey of 56 adults with SCI, 75% indicated that their secondary health conditions were interfering significantly with their ability to socialise, and 64% indicated they significantly impacted their daily living activities (Piatt et al., 2016). Social problems such as difficulty accessing the workplace and gaining societal acceptance within the workplace are critical areas that have much room for improvement (Jongbloed et al., 2007). Despite the negative impact of SCI and resulting sequelae on quality of life, the focus of current research is not meeting needs in autonomic areas (Li et al., 2022). Perhaps one reason for this misalignment of research priorities is the lack of involvement of individuals with SCI in driving research forwards. If research does not include their perspectives, it is less likely to produce relevant and feasible recommendations.

1.3. Bowel care is complex, time consuming, and negatively impacts quality of life

Bowel management after SCI is complex and typically requires regularly scheduled bowel care using various techniques to promote evacuating the bowel, including digital rectal stimulation or manual evacuation, among other options. If hand function is limited, bowel care can be a challenge that may require individuals with SCI to have assistance to facilitate emptying (Figure 4). Bowel management involves not only the physical emptying of the bowels, but also the bowel programme, which includes optimisation of diet and fluid intake, use of assistive devices, participation in regular physical activity, and use of medications.

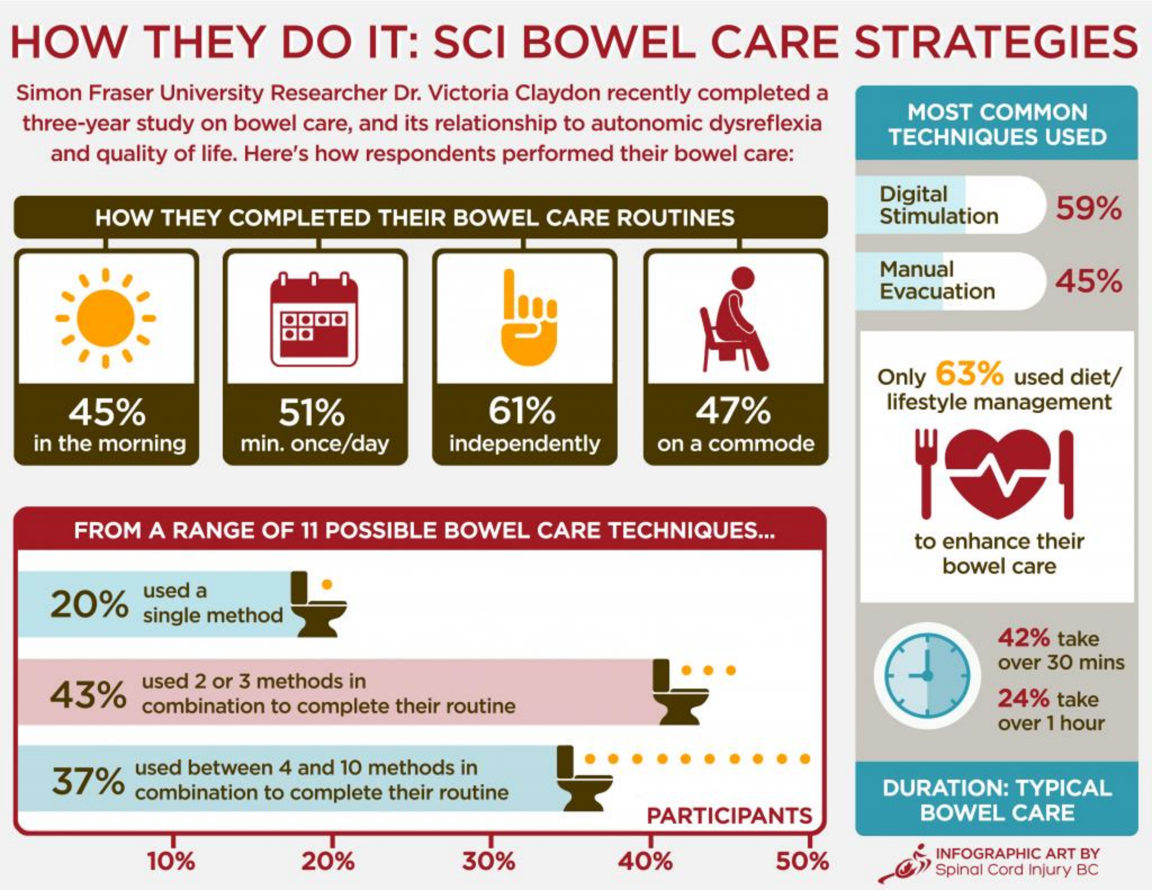


Figure 4. **Bowel care strategies after SCI. Bowel care after SCI is complex and requires multiple methods for efficacious bowel emptying.**

Figure courtesy of Spinal Cord Injury British Columbia.

Completing bowel care after SCI is a time-consuming process and the time taken to complete bowel care is a key determinant of quality of life for individuals living with SCI (Inskip et al., 2018). Clinically, bowel care lasting longer than 60 minutes is considered problematically prolonged (Johns et al., 2021). When examining the time it took to complete bowel care from nine studies (M. Coggrave et al., 2009; M. J. Coggrave et al., 2012; Inskip et al., 2018; Kim et al., 2012; Krogh et al., 1997; Leduc et al., 2002; McCarthy et al., 2020; Pardee et al., 2012; Pires et al., 2018), a weighted average of 14.6% (n=2701) of individuals took over 60 minutes to complete their care. A weighted average of 25.7% of participants (n=1236) from six studies report their bowel care lasts 31-60 minutes (M. J. Coggrave et al., 2012; Inskip et al., 2018; Kim et al., 2012; Krogh et al., 1997; McCarthy et al., 2020; Pires et al., 2018). This is especially troublesome because although 60 minutes is a clinical cut-off for problematic care, many individuals with bowel care lasting less than 60 minutes still consider their bowel care to be problematic (Inskip et al., 2018; Leduc et al., 2002).

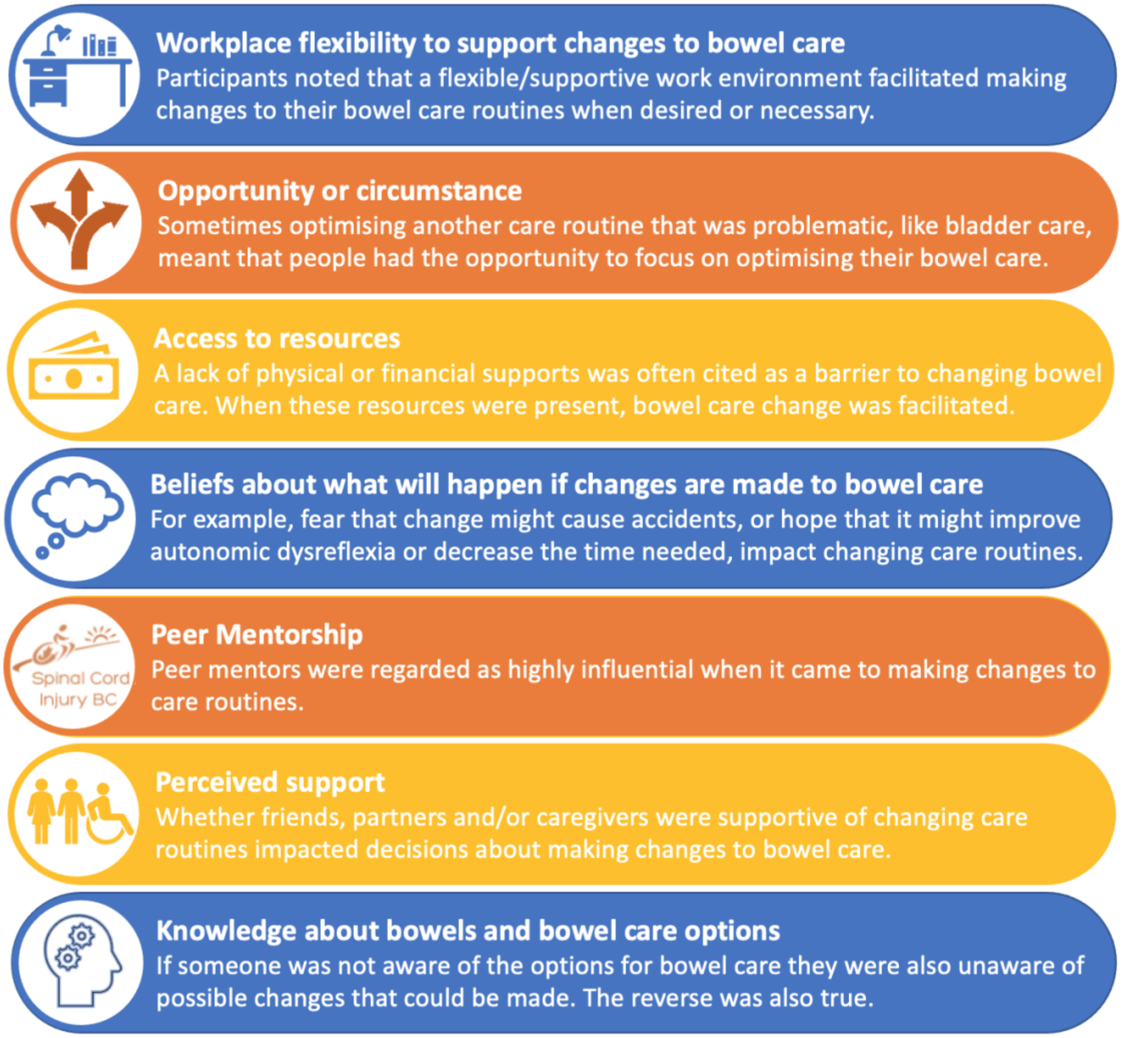
Of those at risk of AD, 49.3% (n=1144) were aware that they experienced bowel-induced AD (M. Coggrave et al., 2009; Inskip et al., 2018). Bowel-induced AD was an independent predictor for QoL of individuals experiencing symptoms (Inskip et al., 2018) and is among the leading reasons why some individuals elect to manage bowel care with an ostomy (M. J. Coggrave et al., 2012; Cooper et al., 2019; Pardee et al., 2012).

Fecal incontinence is a consistent problem for 56.9% (n=4111) of individuals with SCI (Adriaansen et al., 2016; Elmelund et al., 2019; Gong et al., 2021; Hwang et al., 2017; Inskip et al., 2018; Jörgensen et al., 2017; Kannisto & Rintala, 1995; Kim et al., 2012; Krogh et al., 1997; Leduc et al., 2002; Locke et al., 2019; McCarthy et al., 2020; Pires et al., 2018), with the mere risk of fecal incontinence causing a deterioration in QoL (Burns et al., 2015; Gong et al., 2021; Nevedal et al., 2016; Szymanski et al., 2017). Fecal incontinence is a barrier to the pursuit of work (Burns et al., 2015; Lucci et al., 2022), starting new relationships (Burns et al., 2015; Nevedal et al., 2016), and can complicate perianal wound care (Kim et al., 2012), all contributing to reduced QoL. Additionally, the fear of worsening fecal incontinence has been reported as a barrier to changing bowel care practices (Lucci et al., 2022), perpetuating a cycle of apprehension to change bowel care.

Autonomy in bowel care depends on the degree of mobility and hand function (Jörgensen et al., 2017), but when possible, independence of care improves social and emotional well-being by allowing bowel care to remain a private undertaking. The ability to independently perform care routines appears to be a critical factor for physical health-related QoL (Hicken BL et al., 2001; Hwang et al., 2017; Nevedal et al., 2016), a sentiment emphasised in clinical guidelines (Stiens et al., 1997). In one study, individuals with SCI (especially women) commonly expressed the desire to conduct care independently and to limit reliance on others (e.g., care aides, partners, and family) to complete bowel care (Nevedal et al., 2016).

Clinical guidelines for bowel care indicate the importance of maintaining a regular schedule of emptying (Johns et al., 2021). Despite this, the frequency of bowel care as determined from two studies (Kim et al., 2012; McCarthy et al., 2020) shows that a weighted average of 11.8% of individuals completed bowel care less than weekly. This is not surprising because maintaining a regular bowel care schedule can come at the cost of social engagement, work, relationships, and lifestyle (Burns et al., 2015; M. Coggrave et al., 2009; Inskip et al., 2018; Kannisto & Rintala, 1995; Kim et al., 2012; Krogh et al., 1997; Luther et al., 2005; Pardee et al., 2012).

Bowel care is time consuming and frustrating, people are dissatisfied with their bowel care, and yet most individuals with SCI are not making changes to care routines with the goal of improving bowel care. Our lab has previously explored the barriers and facilitators to individuals with SCI changing their bowel care, and the results of that study made it clear that it was important to understand the barriers and facilitators of HCPs in supporting their patients in changing their bowel care (Figure 5) (Lucci et al., 2022). HCPs are essential in supporting health changes, and understanding why they do or do not recommend changes is key to developing a targeted intervention to support changes to bowel care when needed.



Workplace flexibility to support changes to bowel care
Participants noted that a flexible/supportive work environment facilitated making changes to their bowel care routines when desired or necessary.

Opportunity or circumstance
Sometimes optimising another care routine that was problematic, like bladder care, meant that people had the opportunity to focus on optimising their bowel care.

Access to resources
A lack of physical or financial supports was often cited as a barrier to changing bowel care. When these resources were present, bowel care change was facilitated.

Beliefs about what will happen if changes are made to bowel care
For example, fear that change might cause accidents, or hope that it might improve autonomic dysreflexia or decrease the time needed, impact changing care routines.

Peer Mentorship
Peer mentors were regarded as highly influential when it came to making changes to care routines.

Perceived support
Whether friends, partners and/or caregivers were supportive of changing care routines impacted decisions about making changes to bowel care.

Knowledge about bowels and bowel care options
If someone was not aware of the options for bowel care they were also unaware of possible changes that could be made. The reverse was also true.

Figure 5. Barriers and facilitators for individuals with SCI to change bowel care.
Figure courtesy of V.E.M. Lucci & V.E. Claydon.

1.4. While barriers and facilitators to changing bowel care have been explored with people with SCI, the health care provider perspective has not been examined

Recently, Lucci et al. (2022) used the TDF to examine the barriers and facilitators to individuals changing their bowel care practices. They found that four TDF domains largely influenced individuals changing their bowel care, one of which was knowledge (Figure 3). This result showed that individuals were limited in changing their bowel care due to their lack of access to knowledge – they weren’t sure what options were available to improve their care. Knowledge of bowel care options would likely be disseminated from an individual’s health care provider team, whether that be a physician, nurse, care aide, or other HCP. Lucci et al. (2022) stress the importance of HCPs following clinical best practices and their role in supporting a change in bowel care routines of individuals with SCI. It is important for knowledge of bowel care options to flow freely between HCP and individual, especially if there are changes that can be made to bowel care to improve one’s quality of life. Currently, the barriers and facilitators for HCPs to recommend and support a change in bowel care are unknown.

1.5. Adopting an Integrated Knowledge Translation approach ensures research is targeted to the needs of the stakeholder community

Integrated Knowledge Translation (IKT) is defined by the Canadian Institute of Health Research (CIHR) as “a dynamic and iterative process that includes synthesis, dissemination, exchange and the ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products, and strengthen the health care system” (CIHR, 2016). Specific guiding principles for IKT in SCI research have been developed to improve the value of research by ensuring it is as ethical, relevant, and useful as possible, while avoiding tokenism (Gainforth et al., 2021). These guiding principles centre the “meaningful engagement of the right research users at the right time throughout the spinal cord injury research process” (Gainforth et al., 2021) (Appendix A). IKT aims to make knowledge gained through research more useful and relevant for the end-user (Gainforth et al., 2021). Some of the values of IKT include strengthened partnerships and alliances, improved diversity and inclusivity, increased opportunities, recognition of the community being researched, and sustained relationships built on mutual value, trust, and shared power (Gainforth et al., 2021). This can be facilitated by involving a community partner throughout the research process to ensure there is agreement of research relevance, methods, ethics, and dissemination between researchers and end-users.

The IKT approach is especially important since it positions researchers to conduct meaningful and relevant investigations that can support SCI communities, rather than extracting knowledge from people that it may never serve. Current research questions are not always obviously relevant; it is evident that the key research priorities for individuals with SCI are not often the most investigated or funded projects (Li et al., 2022; Simpson et al., 2012). In a survey of 681 individuals, bladder, bowel, and AD were rated as the top priorities for research (Figure 1), yet in practice much of the current research focus relates to restoring voluntary motor control (Anderson, 2004; Li et al., 2022).

The Knowledge to Action Framework (KTA) is a conceptual framework which describes the process of knowledge creation and intervention design, or action, in order to streamline the movement of knowledge into action (Graham et al., 2006). The KTA represents an iterative and dynamic research process involving the knowledge creation funnel and the action cycle, both of which have different phases (Figure 6).

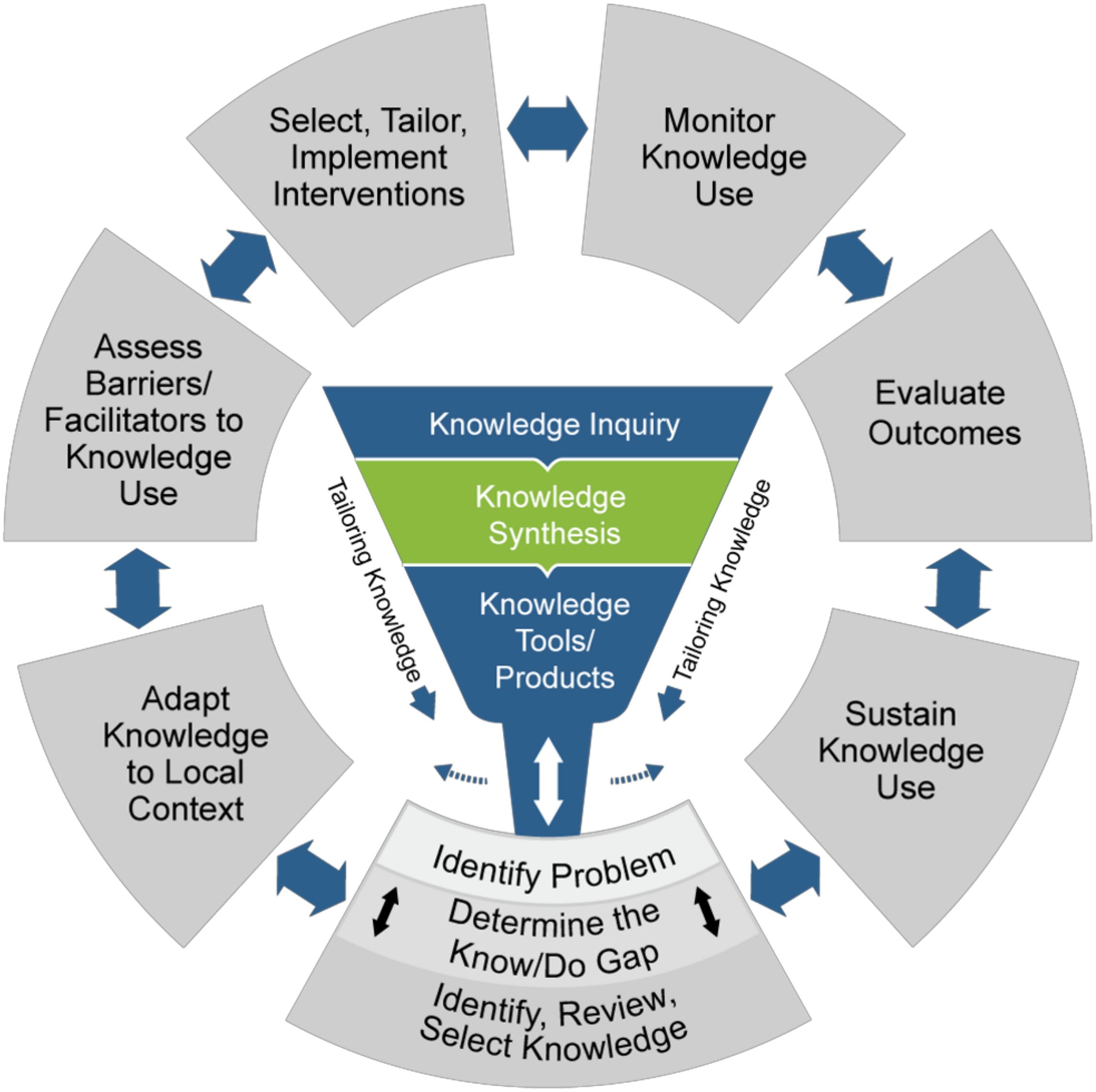
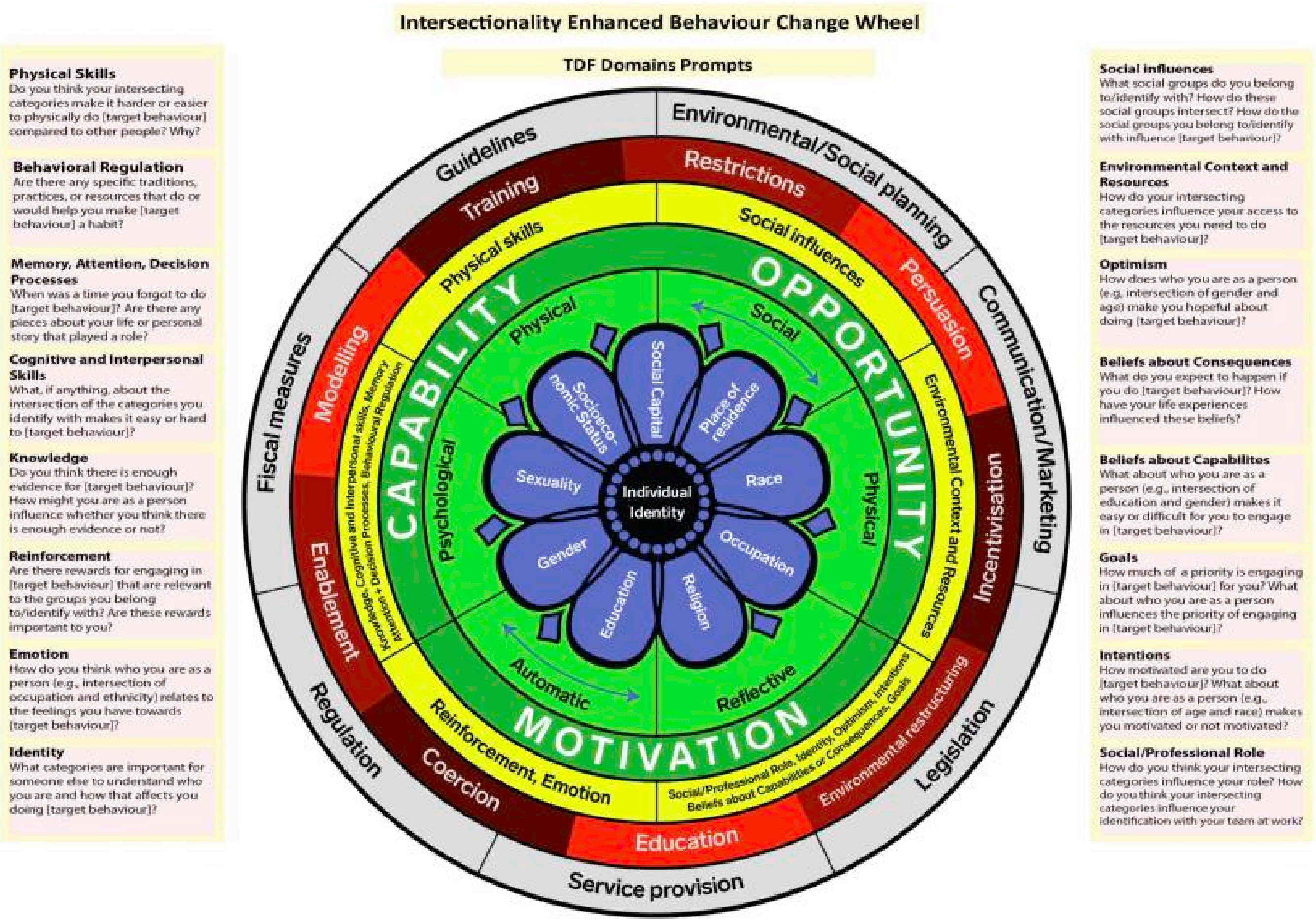


Figure 6. **The Knowledge to Action Framework.**
Straus, S. E., Tetroe, J., & Graham, I. D. (Eds.). (2013). Knowledge translation in health care: moving from evidence to practice. John Wiley & Sons.

There is a need for a qualitative focus to allow for a deeper understanding of the lived experience of individuals with SCI. Given the disconnect between the priorities of people living with SCI and researchers, my project will be conducted according to IKT guiding principles to ensure it is relevant, feasible, and timely.

1.6. Behaviour change science and the TDF are key in changing health behaviour

Behaviour change science seeks to understand the psychological, biological, social, and environmental factors that influence human behaviour (R. West et al., 2020), and can be useful in developing evidence-based interventions for behaviour change that improve health outcomes. Aiming to understand why, how, and for how long behaviour may change is a critical research area. If we can understand the science of behaviour change we can use it to develop interventions in order to prevent harmful behaviours that can lead to worsened health. Using a theoretical framework to understand what helps or hinders a behaviour may increase the likelihood of developing effective interventions (Michie et al., 2008; Michie & Johnston, 2012). Further, when aiming to change health behaviours it is important to consider the potential influence of the intersectionality of one's social/cultural identity and the systems of power that the behaviours are occurring under (Etherington et al., 2020). One theory-based framework, the Theoretical Domains Framework (TDF), is a validated tool composed of many behaviour change theories and was developed to assess health behaviour and inform the design of behaviour change interventions (Cane et al., 2012; Michie et al., 2005). This framework groups 14 behavioural domains (containing a total of 84 constructs) to help identify the barriers and facilitators to completing a behaviour (Cane et al., 2012). The TDF maps onto the COM-B model in the behaviour change wheel (Figure 7). The COM-B model includes six components and works on the understanding that a behaviour happens when the essential conditions of capability (psychological and physical) and opportunity (social and physical) are present, and when an individual is motivated to complete the behaviour (Michie et al., 2011, 2014). The model also integrates the causal link between capability, opportunity, motivation, and behaviour such that increasing one area can feedback to increase another in turn (Michie et al., 2011). The behaviour change wheel can link specific behaviour change interventions to the outcome of the TDF and COM-B model (Michie et al., 2011, 2014). The TDF and the behaviour change wheel can be used to improve the implementation of science into health behaviours (Atkins et al., 2017; Michie et al., 2011). These frameworks have been updated to account for intersectionality (by including specific prompts and an updated design of the behaviour change wheel) to address social/cultural identity and how larger systems of power can affect behaviour change outcomes (Figure 7) (Etherington et al., 2020; Knowledge Translation Program, 2020).



Physical Skills
Do you think your intersecting categories make it harder or easier to physically do [target behaviour] compared to other people? Why?

Behavioral Regulation
Are there any specific traditions, practices, or resources that do or would help you make [target behaviour] a habit?

Memory, Attention, Decision Processes
When was a time you forgot to do [target behaviour]? Are there any pieces about your life or personal story that played a role?

Cognitive and Interpersonal Skills
What, if anything, about the intersection of the categories you identify with makes it easy or hard to [target behaviour]?

Knowledge
Do you think there is enough evidence for [target behaviour]? How might you are as a person influence whether you think there is enough evidence or not?

Reinforcement
Are there rewards for engaging in [target behaviour] that are relevant to the groups you belong to/identify with? Are these rewards important to you?

Emotion
How do you think who you are as a person (e.g., intersection of occupation and ethnicity) relates to the feelings you have towards [target behaviour]?

Identity
What categories are important for someone else to understand who you are and how that affects you doing [target behaviour]?

Social influences
What social groups do you belong to/identify with? How do these social groups intersect? How do the social groups you belong to/identify with influence [target behaviour]?

Environmental Context and Resources
How do your intersecting categories influence your access to the resources you need to do [target behaviour]?

Optimism
How does who you are as a person (e.g. intersection of gender and age) make you hopeful about doing [target behaviour]?

Beliefs about Consequences
What do you expect to happen if you do [target behaviour]? How have your life experiences influenced these beliefs?

Beliefs about Capabilites
What about who you are as a person (e.g., intersection of education and gender) makes it easy or difficult for you to engage in [target behaviour]?

Goals
How much of a priority is engaging in [target behaviour] for you? What about who you are as a person influences the priority of engaging in [target behaviour]?

Intentions
How motivated are you to do [target behaviour]? What about who you are as a person (e.g., intersection of age and race) makes you motivated or not motivated?

Social/Professional Role
How do you think your intersecting categories influence your role? How do you think your intersecting categories influence your identification with your team at work?

Figure 7. The intersectionality-enhanced behaviour change wheel.
The TDF (yellow) and the COM-B model (green) are related and can map to intervention functions (red) and policy functions (grey). Factors of intersectionality (purple) are highlighted in the centre to demonstrate the pervasive influence of individual identity on behaviour outcomes.

Knowledge Translation Program, 2020.

1.7. Autonomic dysreflexia is a key concern for individuals with SCI

When surveyed, the SCI community identified research examining autonomic dysfunction as a high priority (Anderson, 2004; Simpson et al., 2012; Snoek et al., 2004). This is likely due to the dangerous aspects of autonomic dysfunction common to individuals with a SCI at or above a T6 level of injury (including AD) and the magnitude of influence these aspects have on QoL (Figure 1). While chronic hypertension is a well-established cerebrovascular disease risk factor (Phillips et al., 2018; Wang et al., 2015), it is now known that even transient hypertension, if occurring frequently (such as that experienced during AD), also increases the risk of cerebrovascular disease (Phillips et al., 2018; C. R. West et al., 2016). AD has also been associated with myocardial infarction, stroke, and cardiac arrhythmia (Eltorai et al., 1992; Ho & Krassioukov, 2010; Pan et al., 2005; Wan & Krassioukov, 2014).

When strong, often noxious, sensory input enters the spinal cord through intact peripheral nerves, AD can occur. An injury at T6 or above is above the splanchnic sympathetic outflow which controls the splanchnic vascular tone, and in turn can impair the regulation of vasoconstriction of peripheral and splanchnic vasculature (Wecht et al., 2020). High-level injuries put individuals at risk for AD because the visceral upper motor neurons are disrupted, thus preventing vascular capacitance from the splanchnic vascular bed, allowing for the unmitigated rise in blood pressure (Eldahan & Rabchevsky, 2018; Linsenmeyer et al., 2020). The hypertension triggers baroreflex-mediated increases in cardiac parasympathetic drive, causing relative bradycardia and vasodilation. During AD, symptoms of facial flushing, sweating, pounding headaches, blurred vision, nasal congestion, and palpitations are seen above the lesion level (Cowan et al., 2020; Eldahan & Rabchevsky, 2018; Linsenmeyer et al., 2020). Below the lesion sympathetic activation is dominant, with cold, clammy skin, and piloerection (Eldahan & Rabchevsky, 2018; Linsenmeyer et al., 2020). Essentially, AD is a disproportionate response to afferent stimuli that rapidly raises blood pressure to dangerous and uncontrollable levels.

It is generally understood that the sympathetic and parasympathetic branches of the autonomic nervous system have opposite actions on the heart, but they can be simultaneously activated, and it is hypothesized that strong stimuli from both branches at the same time can cause cardiac arrhythmias (Paton et al., 2005; Shattock & Tipton, 2012). This co-activation of nervous system branches may cause the cardiac arrhythmia that commonly occurs during AD (Lucci et al., 2021).

In some cases AD can be “silent”, even with very high blood pressures, and while this lack of symptoms is better tolerated it is not clear that the associated risk is reduced. In fact, because the hypertension of AD will persist until the stimulus is removed, asymptomatic AD may be particularly problematic since the individual would not take action to terminate the episode if they are unaware of it. If AD persists or the triggering stimulus cannot readily be identified, short-duration antihypertensives are given to reduce the blood pressure. This treatment can further complicate secondary conditions since the antihypertensives can dangerously worsen the hypotension that is common in individuals with high-level SCI.

1.8. Thesis outline and project aims

This thesis presents two projects that aim to contribute to an understanding of how to improve quality of life of individuals with SCI. To do this, Chapter 2 uses an IKT approach, aiming to understand the barriers and facilitators to HCPs having conversations about changing bowel care, while Chapter 3 gathers current opinions on the current usefulness of the definition of AD and how it may be improved in the future.

Chapter 2. Barriers and facilitators to healthcare providers having conversations about changing bowel care

2.1. Abstract

Background: Individuals with spinal cord injury (SCI) are dissatisfied with their bowel care routines, yet 71% of individuals with SCI have not changed their care routines for at least 5 years. Recently our team interviewed individuals with SCI who shared that knowledge around bowel care options was needed to facilitate changing routines to optimise care. Health care providers (HCP) are essential in supporting changes to care routines and represent a key resource for knowledge of health care options for people with SCI.

Purpose: We aimed to understand the barriers and facilitators to HCPs having conversations with individuals with SCI about changing bowel care.

Methods: This research was conducted in partnership with a community partner, Spinal Cord Injury British Columbia, and clinicians. Study design was guided by the Capability Opportunity Motivation-Behaviour model (or COM-B) and the Theoretical Domains Framework. Semi-structured interviews were conducted with HCP (n=13, mean age 43.4 ± 13 years) and transcribed verbatim (duration 42.3 ± 16 min). Barriers and facilitators were extracted, deductively coded to TDF domains, then inductively analysed for themes within domains.

Results: Barriers and facilitators were most prevalent within the TDF domains Environmental Context and Resources (27%), Social Influences (19.9%), Beliefs about Consequences (13.4%), and Knowledge (12.5%). Themes were identified in four COM-B constructs: Psychological Capability, Reflective Motivation, Physical Opportunity, and Social Opportunity. Themes within interviews stressed that: knowledge, experience, education & responsibility are all needed; beliefs & intentions shape decisions to have conversations; time & teamwork are valuable yet limited resources; and interpersonal dynamics are present & impactful. Inter-coder agreement was high (Cohen's Kappa=0.72, PABAK=0.93). When linking study results to intervention functions through the BCW, all intervention options are possible.

Conclusion: Changing bowel care takes a village. This study will support the development of targeted interventions that will reduce barriers and enhance facilitators to changing care routines, empowering individuals with SCI to change bowel care when needed, hopefully improving their quality of life.

2.2. Introduction

Spinal cord injury (SCI) affects over 20 million people worldwide(Ding et al., 2022) and not only causes paralysis, but also disrupts the neural pathways that control autonomic bodily processes including control of bowel function. Accordingly, individuals with SCI experience a range of continence challenges. Specifically, neurogenic bowel dysfunction can cause fecal incontinence and constipation. Bowel dysfunction after SCI can be managed with prescribed bowel routines, but the inflexibility of these routines can interfere with the lifestyles of individuals, reducing self-efficacy, impacting self-esteem, and compromising spontaneity and access to activities away from home (Inskip et al., 2018).

In a recent survey, 78% of people with SCI reported being dissatisfied with their bowel care routines, with many reporting that bowel management negatively impacts life activities (Figure 2) (Inskip et al., 2018; Anderson, 2004). Despite this dissatisfaction, 71% of individuals had not changed their bowel care routines in at least 5 years, highlighting a disconnect between dissatisfaction with care routines, and making changes to care routines to improve satisfaction (Inskip et al., 2018). Our team recently applied the Theoretical Domains Framework (TDF) to conduct interviews with individuals with SCI in order to identify barriers and facilitators to changing their bowel care. We found that changing bowel care was heavily influenced by many factors, especially environmental context and resources, beliefs about consequences, social influences, and knowledge (Figure 3) (Lucci et al., 2022). Main themes of barriers and facilitators to individuals with SCI changing bowel care included workplace flexibility, opportunity, circumstance, access to resources, perceived support, peer mentorship, knowledge of physiological processes, and knowledge of bowel care options (Figure 5) (Lucci et al., 2022). Among the other barriers, knowledge stood out as an important target for intervention as individuals with SCI cannot change their bowel care if they are unaware of other options (Lucci et al., 2022). Health care providers are essential in supporting changes to care routines and represent a key resource for knowledge of health care options for people with SCI. However, the factors that influence whether health professionals will recommend or support individuals with SCI to make a change in bowel care are unknown (Lucci et al., 2022). This makes it imperative that we elucidate the barriers and facilitators to HCPs having conversations about changing bowel care with their patients.

In this study, we aimed to understand what helps and what hinders HCPs in having conversations about changing bowel care with their patients with SCI through the use of the intersectionality-enhanced TDF, the COM-B, and the BCW.

2.3. Methods

2.3.1. Ethics

The study was approved by both the University of British Columbia Behavioural Research Ethics Board and the Department of Research Ethics at Simon Fraser University (H21-03341). This study conforms to the principles outlined in the Declaration of Helsinki (World Medical Association, 2013). All participants provided written informed consent at the time of screening and verbal informed consent at the time of interview.

2.3.2. Integrated Knowledge Translation

Integrated Knowledge Translation (IKT) involves the engagement of knowledge users and research partners throughout the research process. To improve the value of this work by ensuring it is as ethical, relevant, and useful as possible, while avoiding tokenism, this research was conducted in accordance with the guiding principles of IKT in spinal cord injury research (Appendix A) (Gainforth et al., 2021). We had the privilege of collaborating with health care providers and our community partner, Spinal Cord Injury British Columbia (SCI BC), who provided valued perspectives that helped shape this work at multiple stages (Appendix B).

2.3.3. Recruitment

The study was advertised to staff at various healthcare facilities by poster with a QR code that directly linked to the intake survey. The study was also advertised on the research participation section of the International Collaboration on Repair Discoveries (ICORD) website (www.icord.org). Participants applied for inclusion in the study through submission of an online form that surveyed demographic information and required written informed consent (Appendix C). Participants were offered a $20 gift card to a location of their choice as an honorarium for their time. Maximum variation sampling (Sparkes & Smith, 2013) was used to confirm maximum representation and was assessed on characteristics including: age, sex, gender, ethnicity, occupation, years in practice, how many patients with SCI they see per year, and whether their workplace was in an urban or rural area. Participants were eligible to participate if they were over 18 years old, a HCP in British Columbia, and could communicate in English. Participants who met inclusion criteria were contacted by email to arrange a convenient time for a one-hour long interview.

2.3.4. Protocol

Semi-structured interviews were conducted over Zoom from February 2022 to January 2023 and were used to identify barriers and facilitators to HCPs having conversations about changing bowel care with their patients with SCI. HCPs were defined as any professional directly involved as a member of a care team for an individual with spinal cord injury. The interview guide (Appendix C) was informed by the Intersectionality-Enhanced Theoretical Domains Framework (Etherington et al., 2020) and the Capability Opportunity Motivation – Behaviour model (COM-B) and developed by the entire research team, including clinicians and our community partner, Spinal Cord Injury British Columbia (SCI BC). Interview questions asked about the factors that may help and/or hinder having conversations about changing bowel care, and did not evaluate the quality of care provided. Ten interviews were conducted, then three additional interviews occurred until no new themes emerged (Atkins et al., 2017). A schematic of the study protocol can be found in Figure 8. Interviews were recorded, transcribed verbatim, and anonymised.

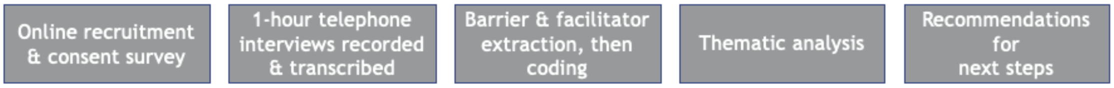


Figure 8. Schematic representation of the study process.
An online screening questionnaire was used to achieve maximum variation sampling. Eligible participants were contacted to participate in 1-hour semi-structured interviews about their experiences in having conversations with individuals with SCI about changing bowel care routines. Interviews were transcribed verbatim, then barriers and facilitators were double-extracted and coded by independent coders. Theoretical domains (from the Theoretical Domains Framework (TDF)) and Capability Opportunity Motivation–Behaviour model (COM-B) components were determined.

2.3.5. Data analysis

Demographic data were summarised using descriptive statistics. The anonymized interview transcripts were evaluated for barriers and facilitators. Barriers and facilitators were double-extracted and deductively coded to TDF domains by two members of the research team. Barriers and facilitators were then inductively analysed for initial themes within COM-B constructs by one member of the research team. Final themes were formed with the guidance of three critical friends and the wider study team (two clinicians and a community partner) to ensure the identified themes and descriptive quotes were representative and resonated with their experiences (Smith & McGannon, 2018; Tracy, 2010).

Deductive analysis

The behaviour of interest was a HCP having a conversation about changing bowel care with their patient who has a SCI. Facilitators were coded as anything that promoted the behaviour, while barriers were coded as anything that prevented the behaviour.

Percent agreement, Cohen's Kappa (Cohen, 1968), and prevalence-adjusted, bias-adjusted Kappa (PABAK) (Byrt et al., 1993) were used to quantify agreement between coders. Inter-coder agreement values over 0.61 indicated "substantial" agreement while values over 0.8 indicated almost perfect agreement (Byrt et al., 1993; Cohen, 1968). Disagreements between coders were resolved with the assistance of critical friends.

Inductive analysis

Inductive thematic analysis was conducted of the barriers and facilitators within the most prevalent TDF domains. A theme was defined as a motif that "captures something important about the data in relation to the research question and represents some level of patterned response or meaning within the data set" (Braun & Clarke, 2006). First, data was examined closely for themes within COM-B constructs, then the research team acted as "critical friends", applying their unique knowledge to review and refine themes.

2.4. Results

2.4.1. Demographic information

We conducted 13 semi structured interviews (2 male). Participant demographics can be found in Table 1. Interviews were an average of 42.3 +/- 16.0 minutes in duration. A range of professions were represented including: nurse, nurse continence advisor, physiatrist, dietician, peer support person, care aide, physiotherapist, occupational therapist, and neurologist. The mean age at time of interview was 43.4 +/- 13.9 years, while the mean duration of years working in the current position was 13.7 +/- 11.8 years and the mean number of patients with SCI these HCP saw per year was 81.6 +/- 105.3. Most participants worked in an urban setting (n=11) and identified as white (n=11) and cisgender (n=13).

Table 1. Demographic and interview information.

Demographic and interview information	
Sample size (Male)	13 (2)
Age	43.4 +/- 13.9 years
Duration working in position	13.7 +/- 11.8 years
Number of patients with SCI seen per year	81.6+/-105.3
Duration of interview	42.3 +/- 16.0 min
Geographical region (urban/rural)	11/2

2.4.2. Data analysis

Deductive analysis

All barriers and facilitators were deductively analysed by TDF domain. The proportion of barriers and facilitators by TDF domain can be found in Table 2. Agreement between coders was high with overall substantial inter-coder Kappa and nearly perfect PABAK (Cohen's Kappa = 0.72 ± 0.12, PABAK = 0.93 ± 03).

Table 2. **Barriers and facilitators by TDF domains.**

TDF domain	Barriers			Facilitators			Overall		
	%	N instances	N interviews	%	N instances	N interviews	%	N instances	N interviews
Environmental context and resources	25.1	51	12	26.0	66	13	27.0	117	13
Social influences	27.1	55	13	12.2	31	11	19.9	86	13
Beliefs about consequences	15.8	32	12	10.2	26	11	13.4	58	13
Knowledge	11.3	23	8	12.2	31	12	12.5	54	13
Memory, attention, and decision processes	5.4	11	7	7.1	18	9	6.7	29	10
Social/professional role and identity	2.5	5	4	6.3	16	7	4.8	21	9
Reinforcement	2.5	5	3	5.9	15	9	3.5	15	11
Beliefs about capabilities	3.4	7	3	5.9	15	9	3.5	15	10
Goals	0	0	0	5.1	13	6	3.0	13	6
Intentions	3.9	8	3	4.7	12	9	2.8	12	10
Skills	2.0	4	3	4.3	11	11	2.5	11	12
Emotions	0.5	1	1	0	0	0	0.2	1	1
Behavioural regulation	0.5	1	1	0	0	0	0.2	1	1
Optimism	0	0	0	0	0	0	0	0	0

The most commonly coded domain within the barriers was Social Influences (n=55). Second most common was Environmental Context and Resources (n=51), followed by Beliefs about Consequences (n=32), and Knowledge (n=23). Combined, these comprised 79.3% of all reported barriers (Figure 9A). The most commonly coded domain within the facilitators was Environmental Context and Resources (n=66) and second most common was both Knowledge and Social Influences (n=31 for both), followed by Beliefs about Consequences (n=26). Combined, these domains accounted for 60.6% of all facilitators (Figure 9B). When examining all combined barriers and facilitators (n=457), Environmental Context and Resources was the most prevalently coded domain (n=117), while Social Influences (n=86), Beliefs about Consequences (n=58) and Knowledge (n=54) were the next most common domains. These four domains accounted for 72.8% of all combined barriers and facilitators (Figure 10).

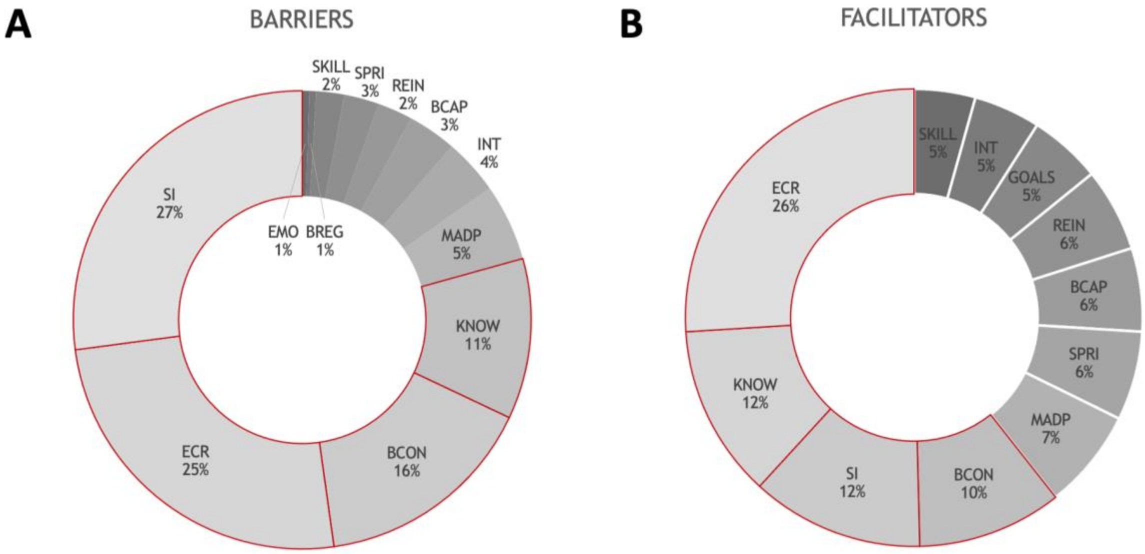


Figure 9. Proportion of barriers and facilitators by TDF domain.
A. Proportion of barriers by domain. B. Proportion of facilitators by domain. The four most prevalent domains are outlined in red. ECR = Environmental Context and Resources, SI = Social Influences, BCON = Beliefs about Consequences, KNOW = Knowledge, MADP = Memory Attention and Decision Processes, BCAP = Beliefs about Capabilities, SPRI = Social Professional Role and Identity, INT = Intention, REIN = Reinforcement, SKILL = Skills, EMO = Emotion, BREG = Behavioural Regulation, GOALS = Goals.

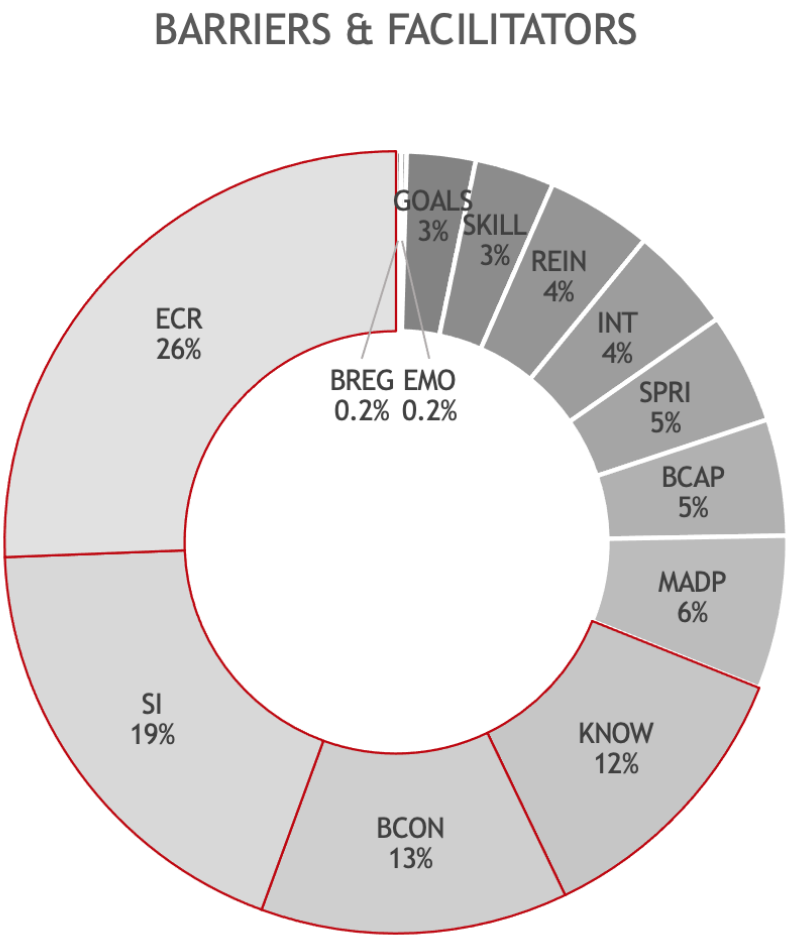
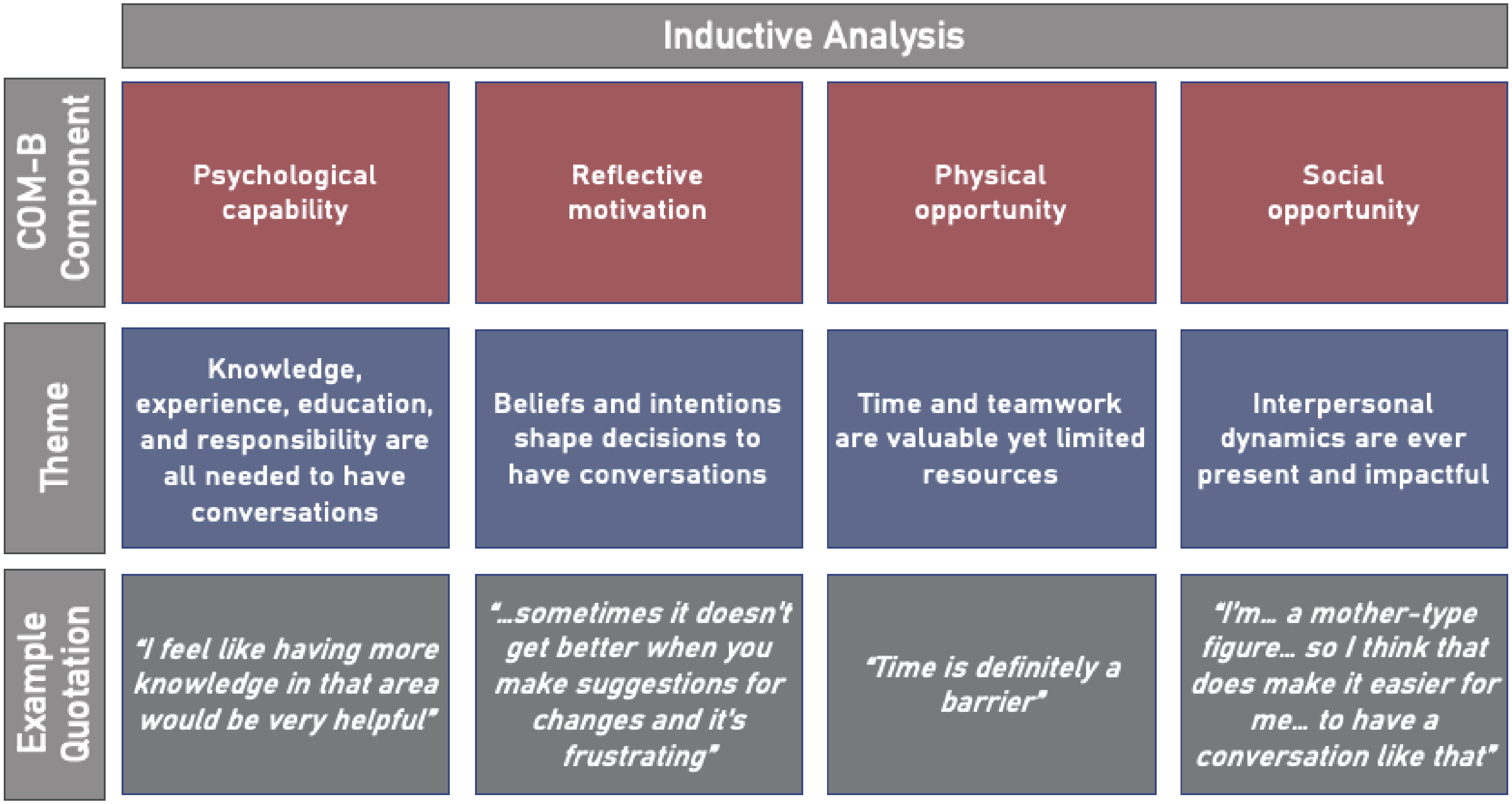


Figure 10. Proportion of total barriers and facilitators by TDF domain.
The most prevalent domains are outlined in red. ECR = Environmental Context and Resources, SI = Social Influences, BCON = Beliefs about Consequences, KNOW = Knowledge, MADP = Memory Attention and Decision Processes, BCAP = Beliefs about Capabilities, SPRI = Social Professional Role and Identity, INT = Intention, REIN = Reinforcement, SKILL = Skills, GOALS = Goals.

Inductive analysis

Inductive thematic analysis was performed in the seven most prevalent TDF domains (Environmental Context and Resources, Social Influences, Beliefs about Consequences, Knowledge, Memory Attention and Decision Processes, Social Professional Role and Identity, and Reinforcement) to ensure all main themes were captured. The research team decided to also conduct thematic analysis within the Goals domain as it was the sole domain in which HCP discussed the reasons for having conversations about changing bowel care. Domains were chosen for thematic analysis based on which were most prevalent in the interviews, and which areas needed to be addressed to improve the situation. Though themes were analysed within the seven most prevalent domains plus Goals, the results often highlight the four most prevalent domains as they held most of the thematic content. The research team acted as critical friends and helped to identify relevant domains and themes. Through linking the most prominent TDF domains to their associated COM-B components, the research team presented the inductive analysis within the COM-B framework, with themes presenting in the constructs of psychological capability, physical and social opportunity, and reflective motivation (Figure 11).



	Inductive Analysis			
COM-B Component	Psychological capability	Reflective motivation	Physical opportunity	Social opportunity
Theme	Knowledge, experience, education, and responsibility are all needed to have conversations	Beliefs and intentions shape decisions to have conversations	Time and teamwork are valuable yet limited resources	Interpersonal dynamics are ever present and impactful
Example Quotation	*"I feel like having more knowledge in that area would be very helpful"*	*"…sometimes it doesn't get better when you make suggestions for changes and it's frustrating"*	*"Time is definitely a barrier"*	*"I'm… a mother-type figure… so I think that does make it easier for me… to have a conversation like that"*

Figure 11. **Results of inductive thematic analysis.**
Inductive analysis results are depicted by COM-B constructs (in red), associated themes (in blue), and representative quotations (in grey) related to healthcare providers having conversations about changing bowel care.

Psychological capability: knowledge, experience, education and responsibility are all needed to have conversations

Psychological capability describes the ability to think, comprehend, and reason, and is most represented by the TDF domains Knowledge, Memory Attention and Decision Processes, and Behavioural Regulation. Participants expressed that being knowledgeable about bowel care and bowel management options was necessary to facilitate individuals with SCI to change their care routines, but that education on the importance of disseminating knowledge with individuals with SCI is missing, and it is not always clear whose job it is to have conversations about changing bowel care. Some participants shared that their lack of knowledge of care options was a barrier to supporting a change in care routines:

> "*I couldn't say what best practice is in bowel care right now with an individual with a spinal cord injury, I couldn't. I couldn't say what the top 3 options are*".

> *"Besides [a transanal irrigation system], like, I don't really know if there's any other kind of different methods of like managing your own bowel care".*

Other participants shared that their bowel care knowledge from prior professional experience and education facilitated their having conversations about changing bowel care:

> *"I feel very comfortable with the breadth of knowledge about how to make adjustments to bowel routines".*

> *"As a physiatrist, we do spinal cord injury-specific rotations, and that is where you are exposed to a greater understanding of how your neurogenic bowel dysfunction impacts physical well being and quality of life, independence".*

> *"I think for me this has been like just years of clinical experience, you know, learning from other patients, and- and you know, knowing that it's never one thing that's gonna improve a bowel routine".*

> "*My background as a nurse and a nurse continence advisor [facilitates talking about changing bowel care] and also I'm comfortable with, with the uncomfortable conversations*".

> "*I have … my nurse continence advisor certification, my nursing background, and interest in the area, and conversations, you know, obviously I learned from the patients as well*".

When asked if they had the knowledge and skills to have a conversation about changing bowel care, one participant conveyed they were knowledgeable and skillful yet aware of a broader lack of knowledge and skills:

> *"Yes, I do. But a lot of people don't. A lot of people that care for the patients don't".*

Participants expressed either a lack of knowledge or acute awareness surrounding where they can refer their patients to, highlighting that referral is a resource, but only if HCPs know who to refer to:

> "*I don't know what the answer is. I don't know how to get, get them more help, I don't know how to stop this thing from happening… so I feel like I, I get inhibited in that way*".

> *"…I don't know if there's any like more support to kind of help the clients like through that".*

> *"I feel like I don't have the kind of like background medical and physiology knowledge... I kind of leave that to the doctors and… we have a special bowel and bladder nurse here".*

> *"I do know who to turn to [for referral]".*

Participants also expressed the need for education and knowledge resources for individuals living with SCI, and information that is available in multiple languages:

> *"We need more community resources and teaching around bowel and bladder and spinal cord injury. Or we just need a really good place that everybody can go to, to learn."*

> *"It, it would be nice if, for the community, there was a lot more information that was in different languages"*

> *"The resources aren't there to teach everybody about bowel and bladder in spinal cord injured patients… and you don't know what you don't know."*

Other participants described how more education would help HCPs have conversations about changing bowel care:

> "*...more like education would make me feel maybe a little bit more comfortable, because then I'll, I'll feel confident about like, what I'm talking about, or if we're changing their bowel routine, like, what I'm kind of recommending or suggesting that they do*".

> "*I feel like having more knowledge in that area would be very helpful*".

> *"I don't know how to help this gentleman, this individual, and we've tried so many things".*

The theme of responsibility describes the HCP's awareness of whether it is or is not their job to have a conversation about changing bowel care, or to follow up with suggestions they have made. One participant noted they do not feel responsibility to have conversations about changing bowel care:

> "*I don't think it is in my- in my job…*".

While another participant expressed they were unsure of whose role it is:

> "...*Feeling like I'm not the best equipped member of their team to be discussing it with them, so yeah, which has its own, like, risks. Like if no one's discussing it with them because we all think that, or something, or they don't have other members on their team to discuss it with them*".

Throughout the interviews, many HCPs expressed concerns regarding the effects of healthcare inequity on their conversations about changing bowel care. Some participants noted differences in access to resources can help or hinder changing bowel care, and that individuals with SCI may be prevented from changing bowel care due to financial expense:

> *"If you have a work safe BC related spinal cord injury, your capacity to access preventative care, to get the medical supplies, medications, equipment, personal care, human resource support is vastly superior than if you have pharma care funding".*

> *"When I have a patient who comes from a, um an extended care type of living situation or residential care, and it doesn't matter what I say, because there aren't the staffing resources to input, influence, any changes anyways, and it makes me bonkers".*

> *“Sometimes changes can be simple, and sometimes like you said financial things. You know people who have good funding and insurance to pay for pads, and medications, and [transanal irrigation] systems, or whatever people choose to use. But if they're paying out of pocket for things like a probiotic that might be helpful with digestion, and things like that, they're probably not going to take it. Even if it's suggested, and it could be helpful, because if they have to pay out a pocket for that item, they might choose to buy food instead of that, right? So you know… how they're funded for things that help with their bowel care is super important”.*

Other participants noted that one’s environmental context and familiarity with systemic processes can be barriers to accessing care, highlighting some major inequities of the current Canadian healthcare system:

> *“If you've got a patient that lives [in a resource-restricted area of town], or something, right, like, that's going to change too, when they don't have access to clean bathrooms, and you know, so they try to find them housing, but that's going to impact that. I think others, or people, as I said, living in small towns, Will they have the same resources up there that they have down here?”*

> *“… the hard thing is that, in general, people who know how to get a referral to a physiatrist are the ones that already have potentially access to greater services because they know how to navigate the system. So we're also missing out a huge part of the population”*

> *“We definitely have a two tiered system.”*

Interviewees were concerned that they might not be the best person to have the conversation about changing bowel care, or that they lacked knowledge and expertise. Participants were also concerned that many health providers felt that way, and their patients may not have access to other resources, causing bowel care considerations to fall through the cracks.

Physical opportunity: time and teamwork are valuable yet limited resources

Physical opportunity describes the availability of the proper environment, time, and resources, and is most represented by the TDF domain of Environmental Context and Resources. Participants expressed that resources are helpful for having conversations about changing bowel care, but availability of resources differs widely. A hierarchy of care was evident when participants described how time, competing tasks, more pressing medical needs, and the nature of shift work can limit their ability to have conversations about changing bowel care:

"*Time is just very limited sometimes. So, we kind of just do it and then let the client know, and then, like, tell them that we'll monitor it and like follow up with it, like, maybe in a few days, or like, in a week's time. But sometimes it's difficult especially if, if we have like, casual staff, or you know, if it's like different staff every single time, like, people will probably fall through the cracks, because it, it's just like kind of hard to maintain that continuity of care when you have like so many different staff like coming in all the time*".

"*Time is definitely a barrier".*

"...I often don't have a lot of time..."

"There's always like acute care needs like if they're having more pressing medical concerns of the exact time that I'm trying to talk to them maybe".

"Just not having the time and then having to pass it on to like another person. So I'm just, I'm not sure about, like, the follow-up, and whether or not that happened, or if it was discussed".

"Yeah, also just the sheer business right? And you know, a patient that's in excruciating pain, or requires tons of monitoring because they are septic or sick or on a ventilator to breathe - those things are going to trump bowels a lot of the time".

While another participant described the importance of a multidisciplinary team, and that lack of access to such a team can be a barrier:

"*It's a little harder because not everybody is seeing the full multidisciplinary team*".

In an urban centre, HCPs benefitted from being part of a diversely knowledgeable healthcare team, with one participant noting:

"*I'm dealing with somebody that maybe has a bit of a language barrier to me, if I feel that they're best spoken to in their kind of mother tongue, in their own language, I will grab*

> *like, the Cantonese speaking nurse because we're all basically on the same level, right, with understanding bowel care*".

When asked to describe any resources that are available to assist in having a conversation with a patient about changing their bowel care, HCPs recognized the unique validity and importance of peer support from community members with lived experience, stating:

> *"Spinal Cord Injury BC, so the peer support network is another valuable tool because there's a different level of or different type of validity that comes from speaking with someone who has to manage neurogenic bowel dysfunction personally"*

> *"Their physician being one, the uh nurse specialists here who does the continence care, there's a gentleman in the community who uh specifically sells uh bladder and bowel products. I think, between those 3 and also the members in the community. So I kind of have like a little black book of like oh, you're getting an ostomy, I know these 3 people, you're doing this. I know these 3 people. So I think peers, professionals, I think [are] the main resources that I have to go to."*

During the interviews, HCPs stressed that time and teamwork were required to have conversations about changing bowel care, and that time was severely limited. Peer support was highlighted as a facilitator to having conversations about changing bowel care.

Social opportunity: interpersonal dynamics are ever-present and impactful

Social opportunity describes the interpersonal influences that shape behaviour, and is most represented by the TDF domain Social Influences. Within the Social Opportunity construct, a theme emerged on intersectionality and interpersonal dynamics. This theme describes how HCPs real or perceived consequences (positive or negative, for themselves or their patients) can encourage or discourage conversations about changing bowel care. One participant mentioned their perceived benefits from having conversations about changing bowel care, indicating that it might improve patient quality of life and strengthen the caregiver-client relationship:

> “*I get a kick out of just being able to inform, educate, provide compassion, to try to find the pathway through, uh, and I do that with, with medical expertise, and hopefully with, with a relatability with, with my patients*“.

Other participants mentioned their perceived negative consequences from having a conversation about changing bowel care, and how a conversation about changing bowel care could have a negative impact on the HCP-patient relationship:

> “*Maybe them not being comfortable talking about it with me. So them kind of shutting down and it maybe impacting the rest of our assessment or relationship, moving forward*”.

> *“Deterrents? Yeah, turning them off from wanting to talk to me further about things”.*

Interestingly, the social/cultural identity of the HCP or the perceived social/cultural identity of their patients also presented as both a barrier and facilitator. Participants mentioned how their identities can help or hinder conversations:

> “*I guess I- I'm a mother, and I am [older], and I am female, so I think that in some ways makes it easier for me to have a conversation with a 25 year old about their bowel routine, because they're like my child so… having a conversation is more, I’m- I'm more like a mother-type figure, I would think, too possibly. And so I think that does make it easier for me to- to do that, to have a conversation like that*”.

> *“I know maybe somebody who's… a quadriplegic sees me move my hands or move my legs, and based off that they feel like maybe I can't understand what their program is about or what they have to go through, that sort of thing.”*

Others noted that the intersectional traits of the individual with SCI also influenced the conversation:

> *“It's also reasonable to keep cultural sensitivity in mind with how comfortable is someone in speaking about bathroom topics.”*

> *“I feel like their personal life situation, who they are as people, all all impacts about their behavior on their bowel routine. So whether they are open to talking about things like that… their personality definitely matters I think”*

“Socioeconomic status would be the biggest one” (Context: do you think your patients' different parts of their social identities influence conversations about changing their bowel care?).

Overall, HCPs commonly expressed that intersectionality and interpersonal dynamics can help or hinder having conversations about changing bowel care.

Reflective motivation: beliefs and intentions shape decisions to have conversations

Reflective motivation describes the processes of conscious planning, intentions, and evaluations, and is most represented by the TDF domains Social Professional Role and Identity, Optimism, Intention, Beliefs about Capabilities, Beliefs about Consequences, and Goals. Within the Reflective Motivation construct, a theme emerged that beliefs and intentions shape decisions to have conversations. This theme describes the encouraging or discouraging influence of HCP beliefs (that having a conversation will or won’t help improve bowel care) on having conversations about changing bowel care. Participants largely expressed that their attempts to have a conversation about bowel care can feel futile. Participants also described that their desire to improve bowel care and patient quality of life can encourage them to have the conversation.

Many participants noted their beliefs that their conversation may not help, stating:

“*… sometimes it doesn't get better when you make suggestions for changes and it's frustrating*”.

“*…that would be a concern, is that sure I can send you to this phone number and then in 6 months’ time somebody will speak to you. So I think that's a bit sort of a depressing thought that this problem is really not going to be addressed, even though there's a flow chart sitting there*”.

While other participants noted their beliefs that their conversation would help improve bowel care and quality of life:

“I actually can make a difference in their bowel routine potentially”

“There's such [an] enormous amount of positive sort of domino things that can happen when somebody has a positive outcome from making changes to their bowel care”

“*I'm actually going to impact their life, and that I'm actually going to improve their bowel function, which will then improve their quality of life*”.

This theme was also present within the TDF domain of Goals, outlining that the HCP’s desire to have or not have a conversation with their patients about changing bowel care can facilitate conversations. One participant noted their desire to have the conversation was holistic and patient-centered:

“*I want to be promoting independence, and understanding, and self-determination, and self-advocacy*”.

However, more often, the desires were centered around improving medical outcomes. Of the 13 facilitators coded to the Goals domain, 62% (n=8) were centered around improving medical outcomes, with one participant sharing their desire:

“*I want to make sure that there is safe, complete emptying of stool contents without propagation of symptomatic hemorrhoids, anal fissures, creation of obstruction, overflow diarrhea. I want to make sure that there isn't an issue regarding compromised skin integrity with moisture imbalance, bacterial imbalance, the associated autonomic dysfunction, whether that's um sometimes you'll get parasympathetic overdrive with their bowel routines where they get really lightheaded, and I want to make sure that they're going to be in a safe environment or not passing out or falling over. I want to make sure they're not going dysreflexic, I want to ensure… that they are not spastic with the bowel routine to the point where their balance is compromised and they're at risk of falls*”.

Throughout the interviews, HCPs expressed the belief that their conversations will help or hinder bowel care, respectively facilitating or preventing future conversations about changing bowel care. The HCP’s intention behind having conversations about changing bowel care mattered; some wanted to promote self-determination while most wanted to improve medical outcomes.

Intervention Options

When linking the COM-B components included in the inductive analysis (psychological capability, reflective motivation, physical opportunity, and social opportunity) to intervention options using a BCW matrix, we determined that all intervention options are available for promoting behaviour change. When discussing intervention options, HCPs emphasized the need for information resources (for themselves and their patients) that are available in various languages. This highlights a potential target area for an intervention.

2.5. Discussion

Through interviewing individuals with SCI, we learned that the barriers and facilitators to individuals with SCI changing their bowel care were mostly represented within the domains of Environmental Context and Resources, Beliefs about Consequences, Social Influences, and Knowledge (Lucci et al., 2022). Our results from HCPs echo these ideas, with the same most prevalent domains identified. Of note, in this study the TDF domain Beliefs about Capabilities was not included in the thematic analysis because its improvement is contingent on the domains of Knowledge and Environmental Context and Resources.

Bowel care is multifactorial and requires diverse knowledge of multiple systems. There was a hierarchy of care evident in both the interviews with individuals with SCI and HCPs that showed the combination of limited resources of HCPs and other more urgent medical needs leads to the deprioritisation of bowel care. While this is understandable, it is not ideal as it can mean that bowel care is never re-examined after an individual leaves acute care, leaving them with a less than optimal care routine which they have to fit their life around. Further, individuals living with SCI noted that access to specialist care is problematic in rural or remote settings and highlighted the importance of HCPs being knowledgeable about bowel care best practices (Lucci et al., 2022). Here we found that that HCPs are not universally aware of bowel care best practices, and that their knowledge differs depending on their occupation and years of experience. The importance of peer mentorship was highlighted both by individuals living with SCI and HCPs, emphasizing that peer mentorship is an under-utilised resource for bowel care knowledge dissemination that could be leveraged to help fill care access gaps.

A problem also became evident in the continuity of care that patients receive. In the interviews, HCPs expressed that it is important for patients to have access to the same HCP over time to ensure there is follow up regarding bowel care routines. Continuity of care may facilitate improvement in bowel care rather than walk-in clinic or emergency visits.

The TDF domain of Goals is the only domain where HCPs discussed medical outcomes. This may elucidate the driving factor for having conversations about changing bowel care; most HCPs are aiming to improve tangible medical outcomes. This will inform our intervention target as if medical outcome goals are met, HCPs may not think to have a conversation about changing bowel care, potentially missing an opportunity to improve an individual's bowel-related QoL despite their bowel care not being a clinical priority. We understand that the current time-limited nature of public healthcare likely contributes to this prioritisation. This is further complicated by the uncertainty of what constitutes problematic bowel care that sometimes reduces the likelihood that problematic care will be addressed. These missed opportunities for improving QoL exemplify the disconnect of priorities between people with lived experience and HCPs, highlighting a key area for improvement.

While discussing questions related to intersectionality, some HCPs did not directly answer the questions. It is not clear whether that was due to their potential discomfort with the topic, or their own understanding of their positionality. Some HCPs did answer the questions directly, but could not imagine how intersectionality (of their own identities or their patients') could help or hinder having conversations about bowel care in any way. This unawareness of the HCPs earned and unearned privileges highlights an opportunity to expand their cultural humility which may be possible by following recent recommendations to develop and implement an anti-racist, trauma-informed cultural humility training for all health workers (Turpel-Lafond & Johnson, 2021). Importantly, the unawareness of privileges or systematic disadvantages does not negate the impact these forces have on the quality of life of individuals with SCI. Interestingly, many HCP discussed the perceived barriers and facilitators of their patients rather than, or in addition to, their own barriers and facilitators. This could further support the recommendation for further cultural humility practice to improve identification of one's own agency or involvement in having conversations about changing bowel care.

2.6. Strengths and limitations

Rather than using one behaviour change theory, this work was strengthened by the use of the TDF, which combines many behaviour change theories. This work also benefitted from following IKT guiding principles and the KTA framework, ensuring knowledge end-users were involved in the pathway from research to practice. These frameworks helped ensure this work was credible and coherent, and that it resonated with all knowledge partners (Tracy, 2010).

It was unclear whether participants chose to participate because they were already motivated to talk about bowel care, or already felt knowledgeable about bowel care options. If participants self-selected in this way it would mean that our data represent the best-case scenario for HCP knowledge and comfort with having conversations about changing bowel care. This sentiment was expressed by HCP in their interviews where they expressed the belief that they themselves know how to have conversations about changing bowel care, but know that others do not.

Some participants in our sample live with chronic health concerns. We are hopeful that their perspectives lend additional validity to our work.

Recruitment was challenging, as could be expected when trying to contact HCPs during a global pandemic and Canadian healthcare crisis. We intended to use maximum variation sampling to select participants from a maximal diversity of identities, careers, and career stages, but could only achieve a convenience sample due to low recruitment. We did achieve variation in HCP age, occupation, number of years practicing, and number of patients with SCI. Despite attempting maximum variation sampling, we interviewed mostly female participants who work in the lower mainland of BC and do not identify as an ethnic minority, and we did not interview a general practitioner. It is unclear if females were more willing to discuss bowel care or their work practices, if there are more female HCPs in this field, or if there is another contributing factor to the sex bias observed. We recognise that more fulsome diverse sampling was not possible and potentially limited the universal applicability of our results, while recognising that we did reach thematic data saturation. Of note, our results were representative of the BC sample of HCP and subsequent interviews with HCP in the United States also produced similar themes. We anticipate a more diverse sample would have strengthened our results, likely increasing the representation of the Knowledge domain, but would not have greatly changed thematic results.

2.7. Future directions

We suggest the immediate creation and distribution of a “Red Flags and Resources” (when is bowel care problematic and what to do when it is) education intervention to support HCP in having a conversation about changing bowel care.

Clearly, an intervention is needed to educate HCP about how to have a conversation about bowel care and whose responsibility it is to have that conversation. Everyone who interacts with an individual with SCI needs to understand what successful care looks like and what makes care problematic or unacceptable. This will help treatment pathways as HCP will be able to confidently have a conversation about bowel care with their patients. It is also necessary for HCP to know what they would do to solve problematic bowel care and who they would refer to if they have exhausted their own treatment options. Noticeably lacking in the interviews was discussion of referral to GI specialist doctors, who logically could be a common point of referral for bowel care issues, if they were knowledgeable about neurogenic bowel dysfunction.

2.8. Conclusion

There is a problem with the dissemination of bowel care knowledge from HCPs to individuals with SCI. There are many factors that influence whether HCPs have conversations about changing bowel care with their patients. These factors mainly relate to psychological capability, reflective motivation, and social and physical opportunity. This work will help shape the development of timely and necessary interventions that will support HCPs to have more conversations about changing bowel care, thereby supporting individuals with SCI in changing their bowel care and hopefully improving their quality of life.

Chapter 3. Dysreflexic Dilemma: do we need a revised definition for autonomic dysreflexia?

Autonomic dysreflexia (AD) is a condition unique to individuals with autonomically-complete, high-level (T6 or above) spinal cord injury (SCI) and refers to sudden episodes of hypertension that are provoked by sensory stimuli below the level of the spinal lesion (Figure 12). The sympathetically-mediated rise in blood pressure can be profound and unpredictable, and is often accompanied by symptoms, including pounding headaches, dizziness, nausea, shortness of breath, visual disturbances, and palpitations, often with facial flushing and sweating above the lesion level, and/or cold clammy skin with piloerection below the lesion level (Eldahan & Rabchevsky, 2018; Inskip et al., 2018; Linsenmeyer et al., 2020). In response to the hypertension, baroreflex-mediated bradycardia and vasodilatation (above the lesion level) occurs in an attempt to restore blood pressure. Often these are insufficient to adequately compensate, and blood pressure remains elevated until the triggering stimulus is removed.

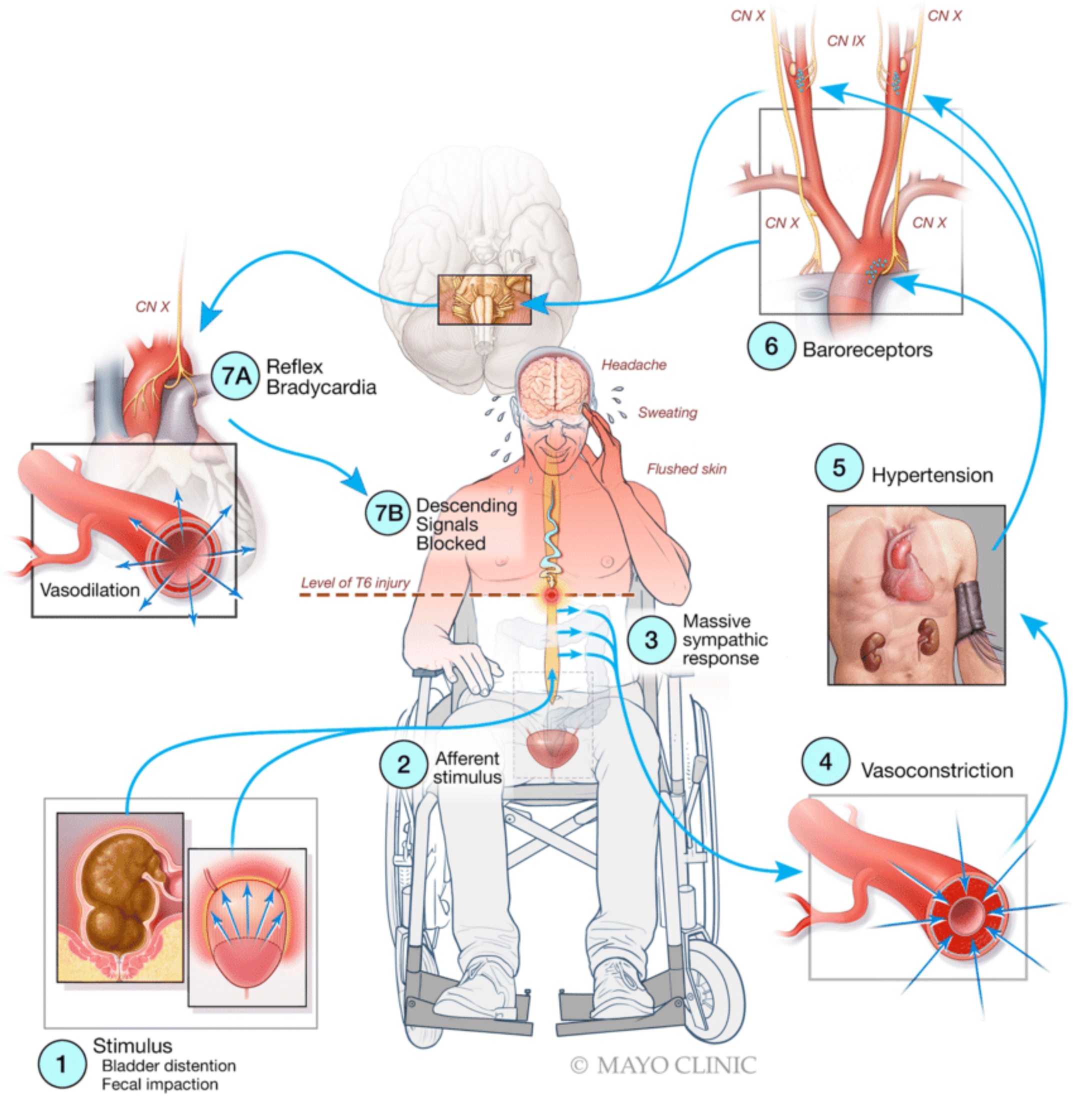


Figure 12. Mechanism of autonomic dysreflexia.
After autonomically-complete spinal cord injury (SCI) at T6 or above, autonomic dysreflexia (AD) occurs when sensory stimuli (typically visceral stimuli such as bladder distention or fecal impaction) provoke a massive sympathetic discharge leading to widespread vasoconstriction and hypertension. The profound hypertension elicits baroreceptor-mediated reflex bradycardia and vasodilation in regions under supraspinal control in an attempt to reduce blood pressure. Often this is insufficient to adequately compensate and blood pressure remains elevated until the stimulus is removed. Combined high cardiac sympathetic drive from the dysreflexic response, and baroreflex-mediated increases in cardiac parasympathetic outflow, a phenomenon known as autonomic conflict, may be proarrhythmogenic. In some cases AD can be “silent”, even with very high blood pressures, and while this is better tolerated it is not clear that the associated risks are reduced. In fact, because the hypertension of AD will persist until the stimulus is removed, asymptomatic AD may be particularly problematic because the individual cannot take action to terminate the episode (identifying and removing the sensory stimulus) if they are unaware of it. Reproduced with permission from Mayo Foundation for Medical Education and Research. All rights reserved.

3.1. Autonomic dysreflexia is associated with significant morbidity and mortality

Individuals with AD report the condition among their top priorities for improving quality of life (Anderson, 2004; Carlozzi et al., 2013; Inskip et al., 2018), noting that it interferes with a wide array of activities of daily living including exercise, work, sexual activity, sleep, social activities, driving, and rehabilitation (Inskip et al., 2018). AD occurs in up to 90% of individuals with tetraplegia or high paraplegia (Kursh et al., 1977; Lindan et al., 1980; Yarkony et al., 1986), with the potential to occur multiple times a day (Hubli et al., 2015). AD can be triggered by numerous sensory stimuli (from pressure wounds to ingrown toenails)(Inskip et al., 2018); however, AD is most often triggered by visceral stimuli from the bladder or bowels (Bycroft et al., 2005).

Although AD can be symptomatic, it can also present asymptomatically, termed "silent AD" (Huang et al., 2013). The differences in symptomology between individuals is poorly understood and the associated risk of silent AD remains unclear. It is possible that silent AD may impair the recognition of an episode of AD, which has implications for management and therefore resolution of the hypertensive response.

In addition to its impact on quality of life, the paroxysmal hypertensive response during AD has been associated with significant morbidity and mortality (Bycroft et al., 2005; Jacob et al., 2005; Lindan et al., 1980; Wan & Krassioukov, 2014). These extreme blood pressure responses have been associated with seizures (Kursh et al., 1977; Lindan et al., 1980; Yarkony et al., 1986), cardiac arrest (Colachis & Clinchot, 1997), transient aphasia (Colachis & Fugate, 2002), myocardial ischaemia (Ho & Krassioukov, 2010), and stroke/cerebrovascular accident (Eltorai et al., 1992; Jacob et al., 2005; Kursh et al., 1977; Pan et al., 2005; Vallès et al., 2005). Cardiac arrhythmia can occur due to the combined high cardiac sympathetic activity due to dysreflexia and concurrent high parasympathetic activity mediated by the baroreflex response – a phenomenon known as autonomic conflict (Claydon et al., 2006; Forrest, 1991; Lucci et al., 2021; Pine et al., 1991).

While there is evidence that cerebral autoregulatory responses to *hypo*tensive episodes are impaired in those with high-level SCI (Nightingale et al., 2020; Sahota et al., 2011), the impact of *hyper*tension caused by AD on cerebral autoregulation is less clear, with some evidence that it may be better tolerated than hypotension (Phillips et al., 2013; Sahota et al., 2022). Regardless of autoregulatory responses, rodent models of high-level SCI have shown that frequent and severe episodic hypertension results in cerebrovascular remodeling in a similar manner to that observed with chronic hypertension, with increased vascular stiffness and reduced distensibility of cerebral arteries that was associated with reductions in cerebral blood flow and impaired short-term memory (Jia et al., 2016; Phillips et al., 2016, 2018; Sachdeva et al., 2020). Accordingly, it is likely that severe hypertension associated with AD has negative effects on the cerebral vasculature. Whether smaller blood pressure increases with mild AD are equally detrimental is not known.

3.2. Current clinical definition

The current Paralysed Veterans of America (PVA) and International Standards to document Autonomic Function following Spinal Cord Injury (ISAFSCI) criteria define AD as an increase in systolic blood pressure of >20 mmHg from baseline (Krassioukov et al., 2021; Wecht et al., 2021). The PVA specifies in their definition of AD that the lesion level must be at T6 or above while the ISAFSCI does not (Krassioukov et al., 2021; Wecht et al., 2021). In recognition of the many possible triggers for AD, and the possibility of "silent" AD, neither situational triggers nor symptoms are considered in the definition. Level of injury is also not explicitly included in the definition. The strengths of this approach are its simplicity, and inexpensive, accessible evaluation. It is also compatible with other classifications of abnormal changes in blood pressure, such as the definition of orthostatic hypotension (a reduction in systolic blood pressure of greater than or equal to 20mmHg when standing) (Freeman et al., 2011) and orthostatic hypertension (an increase in systolic blood pressure of >20mmHg and exceeding 140mmHg when standing) (Jordan et al., 2020). However, questions regarding the definition of AD have been consistently present in the literature (Karlsson, 1999; Kirshblum et al., 2021; Sahota et al., 2022; Shergill et al., 2004; Solinsky & Linsenmeyer, 2019; Yee et al., 2022).

The current definition considers AD from a perspective of presence or absence based on whether the systolic pressure increases above this threshold of 20mmHg. However, it is unknown whether the exact stimulus is for AD-related harm is the maximal blood pressure experienced, the magnitude of change in blood pressure, the duration of blood pressure elevation (the length of the AD episode), simply whether AD is present or not, or any combination of these considerations. The defined increase in systolic blood pressure of >20mmHg is a relatively small rise in blood pressure and is likely well tolerated. In reality, blood pressure increases during AD typically far exceed this threshold (Figure 13) (Claydon et al., 2006; Lucci et al., 2017; Sahota et al., 2022). In addition, because of concurrent and severe supine and orthostatic hypotension in individuals with SCI, a 20mmHg increase in systolic blood pressure may remain within the normotensive range and thus may not be clinically problematic. This concept has been noted in other definitions of hypertensive responses, such as the recent consensus statement on orthostatic hypertension, which requires both an increase in systolic blood pressure more than 20mmHg *and* an absolute systolic blood pressure ≥ 140 mmHg (Jordan et al., 2020).

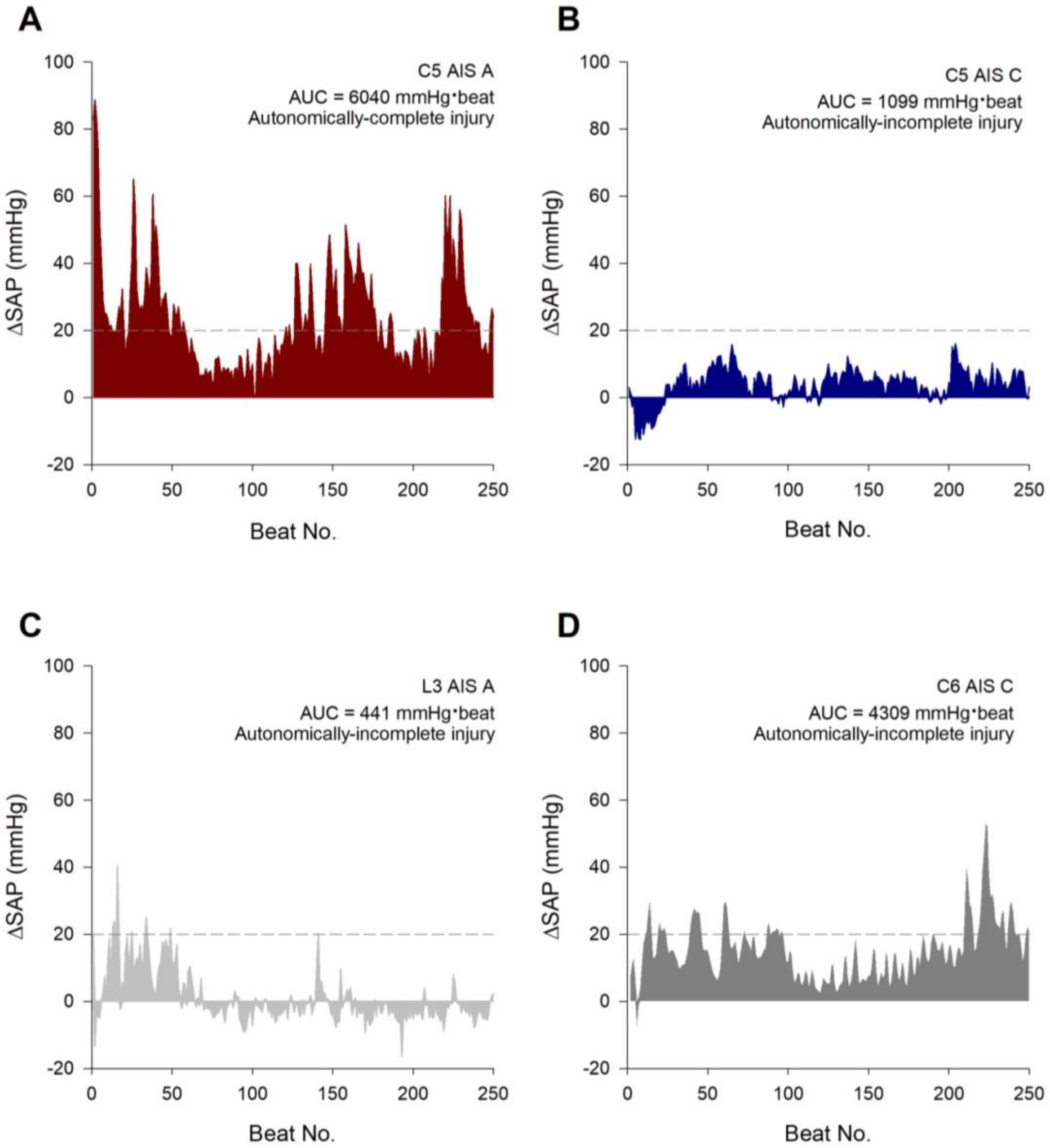


Figure 13. Beat-to-beat changes in systolic blood pressure in three participants with spinal cord injury (SCI) during urodynamics testing.

In A, responses are shown from an individual with a high-level autonomically-complete injury with profound AD and prolonged and severe hypertension. In B, responses are shown from an individual with a high-level autonomically-incomplete injury with preservation of cardiovascular autonomic control, in whom the blood pressure response does not meet criteria for autonomic dysreflexia (AD). In C, responses are shown from an individual with a low-level autonomically-incomplete lesion. Despite not having an injury compatible with the known physiology of AD, this individual technically meets the current blood pressure definition of AD. In D, responses are shown for an individual with a high-level autonomically-incomplete lesion with preservation of cardiovascular autonomic control. Despite not having a physiological substrate for AD, their systolic blood pressure increases more than 20mmHg during urodynamics, raising the possibility for misinterpretation of the response as AD. Autonomic completeness of injury to cardiovascular pathways was inferred from the absence of low frequency oscillations in blood pressure and low plasma noradrenaline levels. Abbreviations: SAP, systolic arterial pressure; AUC, area under the curve; AIS, American Spinal Injury Association (ASIA) Impairment Scale. Adapted with permission from “Cardiovascular and cerebrovascular responses to urodynamics testing after spinal cord injury: The influence of autonomic injury” by I.S. Sahota et al., 2022, Front. Physiol., 13(977772). Copyright 2022 Sahota, Lucci, McGrath, Ravensbergen and Claydon.

Having equal but opposite definitions for conditions of hypotension and hypertension is convenient, but it may be that the impact of increases and decreases in blood pressure on morbidity and mortality are not equal. For example, increases in blood pressure of this magnitude may be better tolerated by the cerebral circulation (Aaslid et al., 2007; Brassard et al., 2021; Numan et al., 2014; Panerai et al., 2018; Sahota et al., 2014, 2022; Tzeng et al., 2010) than equivalent decreases in blood pressure (Sahota et al., 2011).

Defining AD is also challenging when considering the response as an increase in blood pressure relative to baseline, because there can be drastic individual differences in resting blood pressure in the SCI population. Accordingly, the magnitude and impact of AD might vary tremendously between individuals.

3.3. The risk of misidentification of autonomic dysreflexia

In using the current definition, there is also a potential for misdiagnosis of AD. For example, a recent report demonstrated that that 11/12 individuals with lesions that were not compatible with the known physiology of AD experienced a rise in systolic blood pressure that met the current definition of AD during urodynamics testing (Figure 13C and D) (Sahota et al., 2022). This may reflect that, as in the able-bodied, individuals with SCI can experience systolic blood pressure increases of 20-30mmHg (known as “white coat hypertension”) as a consequence of anxiety induced by physiological monitoring in a medical environment (Owens et al., 1999; Solinsky & Linsenmeyer, 2019). Indeed, this phenomenon was noted as a potential cause for misdiagnosis of AD when considering blood pressure alone, and may explain the cases of AD that have been reported in individuals with injuries below T6 (Solinsky & Linsenmeyer, 2019). If we wish to define AD more accurately, without capturing extraneous phenomena that may also be raising blood pressure, it may be useful to incorporate additional considerations in the definition of AD.

3.4. Possible considerations when evaluating autonomic dysreflexia

Perhaps unsurprisingly, challenges with the definition of AD have led to many previous considerations for alternative or additional criteria, combining a rise in systolic blood pressure with other relevant measures in an attempt to increase the sensitivity of the definition. In many cases these alternative definitions have suggested increasing the magnitude of the blood pressure rise that is considered indicative of AD, with proposed increases in systolic blood pressure ranging from 30 mmHg (Krassioukov et al., 2009) to 50 mmHg (Shergill et al., 2004), or increases in systolic pressure by at least 20%, which in a normotensive individual would equate to an increase of about 25 mmHg (Karlsson, 1999; Silver, 2000). Others suggested a blood pressure rise to a finite level, such as in excess of 150 mmHg (Kirshblum SC et al., 2002) or 160 mmHg (Linsenmeyer et al., 1996). Additional proposed measures have included consideration of AD symptoms (Hubli et al., 2015; Lindan et al., 1980) sometimes in combination with 24-hour ambulatory blood pressure monitoring (Hubli et al., 2015), incorporation of a criterion related to a rise in diastolic blood pressure (Kirshblum et al., 2021), or the creation of an AD severity continuum (Courtois et al., 2008). In keeping with the consensus definition of orthostatic hypertension, it may make sense to include a requirement for both an increase in systolic blood pressure *and* an absolute systolic blood pressure threshold, which would negate AD events that occur within the normotensive range.

Most recently, the suggestion to include a concurrent heart rate criterion has been considered as a promising criterion to improve the definition of AD (Sahota et al., 2022; Yee et al., 2022). AD typically presents with baroreflex-mediated bradycardia (<60 beats per minute), in a dose-dependent manner (Figure 14). The presence of bradycardia during an episode of suspected AD could help discriminate other physiological responses that may be confused with AD, including white coat hypertension (Rietchel et al., 2023; Yee et al., 2022), because anxiety-induced elevations in blood pressure are commonly accompanied by tachycardia, or at least the absence of bradycardia (Solinsky & Linsenmeyer, 2019). Indeed, bradycardia was found to be present in over 73% of all AD episodes measured through 24-hour ambulatory blood pressure monitoring (Yee et al., 2022). Concurrent bradycardia was also noted in 65% (Rietchel et al., 2023) and 85% (Claydon et al., 2006) of individuals with SCI during AD provoked by penile vibrostimulation, and 50% (Rietchel et al., 2023) and 89% (Sahota et al., 2022) of those undergoing urodynamics testing. Of note, bradycardia was more prevalent in those with documented severe autonomic injury to descending cardiovascular pathways (Claydon et al., 2006; Sahota et al., 2022), possibly reflecting that the hypertensive episodes associated with bradycardia were true AD responses, and those that were not associated with bradycardia were obtained in individuals with less severe autonomic injuries and perhaps reflected discomfort or sexual responses during these medical procedures. For instance, including a requirement for concurrent bradycardia within the definition of AD resulted in 89% of participants with autonomically-complete injuries meeting criteria for AD during urodynamics testing, compared with 15% of participants with autonomically-incomplete injuries (Sahota et al., 2022). Without consideration of the concurrent heart rate response, 85% of those with autonomically-incomplete injuries met criteria for AD during urodynamics testing, despite having a low probability of experiencing AD based on their lesion level and severity (Sahota et al., 2022). Another potential benefit to considering heart rate responses during AD is the potential for individuals with SCI to use the heart rate response as a proxy for the severity of their AD in cases where the blood pressure is not known. Given the dose-response relationship noted, it may be that the severity of the bradycardic response could provide a simple accessible biofeedback signal from wearable sensors e.g. in smart watches, to indicate the severity of the AD.

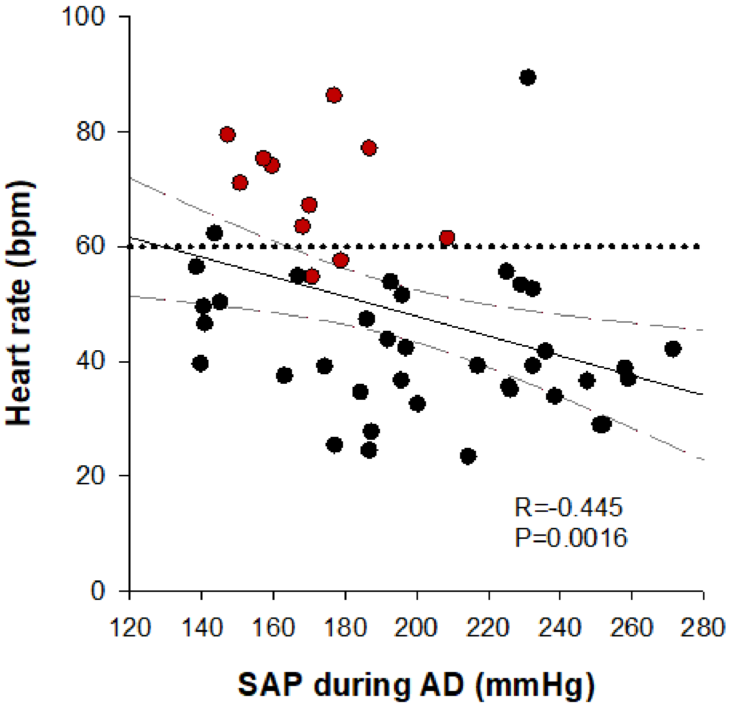


Figure 14. **Heart rate responses during autonomic dysreflexia (AD).**
There is a dose-dependent decrease in heart rate that accompanies the blood pressure rise associated with autonomic dysreflexia initiated by bladder and bowel stimuli. In almost every case, autonomic dysreflexia is accompanied by bradycardia (heart rate <60bpm, dotted line). Individuals shown in red have lesions not compatible with the known physiology of AD. The blood pressure increases they experienced with these uncomfortable medical procedures were rarely associated with bradycardia. Abbreviations: AD, autonomic dysreflexia; SAP, systolic arterial pressure. Data taken from Sahota et al (2022) and Lucci et al (2020).

While incorporating a bradycardic heart rate criterion might improve the sensitivity and specificity of AD diagnosis, there are potential problems with this approach. In particular, some studies have reported cases of tachycardia during AD (Hiekey et al., 2004; Karlsson, 1999; Kewalramani, 1980; Lindan et al., 1980; Scott & Morrow, 1978; Solinsky et al., 2018). It may be that these cases of AD with tachycardia actually reflect tachyarrhythmia associated with autonomic conflict during AD (Collins et al., 2006; Lucci et al., 2021). Certainly, it is important that any heart rate considerations are only evaluated during sinus rhythm. Another possibility is that the tachycardic responses reported during AD reflect misidentification of AD due to the challenges with the diagnostic criteria noted above, other confounding responses such as white coat hypertension, or blood pressure increases occurring during discomfort, exercise, activity, or sexual arousal that might be associated with higher heart rates.

Some groups have included symptoms in the evaluation of AD (Hubli et al., 2015), and while this is not a perfect solution because of the possibility for silent AD, noting any associated symptoms could be useful to aid understanding of the impact the condition is having on the quality of life of individuals experiencing AD. Certainly, because symptoms can be profound and debilitating at times, symptom presence can prove to be an important component of patient history, allowing for both the individual living with SCI and the practitioner to understand the unique triggers for severe and disabling AD.

3.5. Future considerations

The current definition of AD is simple and readily adopted for clinical and research use. However, there is potential for misidentification of AD during blood pressure increases that are attributable to other physiological phenomena. This is especially evident in those with autonomically-incomplete lesions, and contributes to a mixed body of research, with the possibility for confusion of what AD is or can be, and with important implications for research on AD evaluation and treatment, as well as clinical management. It may be that consideration of other factors in the definition of AD could improve sensitivity and specificity in cases where there is uncertainty about the cause of an increase in blood pressure. Additional consideration of whether the cardiovascular and cerebrovascular risks associated with AD might be better predicted through alternate quantification of AD is needed.

Chapter 4. Discussion

4.1. Overview of objectives and main findings

In this chapter, I recapitulate the main findings of the work, and discuss their implications, limitations, and the future directions for these topics. The overall goal of this work was to move towards understanding how to improve the quality of life of individuals with SCI. To do this, I used an IKT approach to: 1) understand the barriers and facilitators to HCPs having conversations about changing bowel care; and 2) discuss the current usefulness of the definition of AD and how it may be improved in the future.

4.1.1. Health care provider perspectives on changing bowel care practices after SCI

In Chapter 2, the main objectives were to: 1) understand the barriers and facilitators to HCPs having conversations about changing bowel care with their patients with SCI; and 2) to identify possible behaviour change implementation options. The objectives were investigated through semi-structured interviews with 13 HCPs. The main thematic findings from Chapter 2 were:

- Knowledge, experience, education, and responsibility are all needed to have conversations
- Beliefs and intentions shape decisions to have conversations
- Time and teamwork are valuable yet limited resources
- Interpersonal dynamics are ever present and impactful

These themes inspired the creation of an immediate resource, “Red Flags and Resources” that aims to provide knowledge of what makes bowel care problematic and what the referral mechanisms are for patients with problematic bowel care. The data highlighted an immediate need for more knowledge about bowel care after SCI, and more knowledge of referral mechanisms for problematic bowel care. These needs were evident when HCPs discussed how their lack of knowledge prevented them from having conversations about changing bowel care. An immediate educational resource has the potential to address these needs and support HCPs in having conversations about bowel care. This resource will be developed in partnership with behaviour change scientists and our community partner, and may immediately improve the QoL for individuals with SCI who desire a change in bowel care. After these initial knowledge gaps are addressed it may be helpful to develop systemic interventions (such as in-person or online trainings) to support HCPs in delivering the quality of care they want to, but currently feel too limited to deliver. When investigating the possible behaviour change implementation options, we found all options are possible. This means any intervention can be created to reduce the barriers and leverage the facilitators to HCPs having conversations about changing bowel care.

While it was not our area of interest, we would be remiss to omit that many of the HCPs we interviewed commented on general difficulties with providing the quality of care they wish to deliver. These HCPs noted that the healthcare system is not structured in a way to give them the time required to address patient concerns in a compassionate way, that patients may receive differing levels of care based on whether they are using the public or private systems, and that patient care is also influenced by their social/cultural identities, especially their socioeconomic status.

4.1.2. Perspectives on the definition of AD

In Chapter 3, the main objectives were to: 1) summarise the current literature regarding the definition and diagnosis of AD; 2) discuss the strengths and weaknesses of the current definition; 3) discuss potential avenues for refining the definition of AD, both from the literature and from our panel of experts; and 4) call for a larger discussion and consideration on the definition of AD. These objectives were addressed through a review of the literature and collaborative discussion from experts in the field including a community partner (SCI BC), clinicians, and researchers. The highlights from Chapter 3 were:

- There are differing definitions of AD between various guidelines and within the literature
- The current definition of AD is easy to use, but can misclassify other physiological phenomena as AD
- The definition of AD may be refined through inclusion of additional criteria
- We need to understand the benefits and drawbacks of refining the definition of AD, taking into account various stakeholder perspectives including individuals with SCI, clinicians, and researchers.

Ultimately, we understand that there is not an obvious amendment that we are currently recommending. Rather, we (a group of various stakeholders) are raising this as a point of discussion for the field to consider. We hope these thoughts encourage further questions surrounding what makes this definition useful, who it is currently serving, and how we can make it more helpful for all stakeholders.

4.1.3. Implications of findings

Chapter 2 provides insight into what is helping and hindering HCPs having conversations about changing bowel care. This insight fills a critical gap in the literature, identifying target areas for behaviour change interventions. The BCW suggests the behaviour change intervention options that will be likely to change behaviour based upon the results of barriers and facilitators investigations, such as that in Chapter 2 (Michie et al., 2014). Possible options for intervention functions include education, persuasion, incentivization, coercion, training, restriction, environmental restructuring, modelling, and enablement (Michie et al., 2014). When examining which options were recommended for changing the behaviour of HCPs having conversations about changing bowel care, we found that all intervention functions are potentially relevant. This means that further analysis is required to determine all of the most appropriate intervention functions prior to development and implementation. Hopefully, this work will translate into effective behaviour change interventions that will make real-world improvements in the bowel-related QoL of individuals with SCI.

Chapter 3 provides thoughts on the definition of AD provided a starting point for a discussion between individuals with SCI, community organizations, clinicians, and researchers on the definition of AD. Hopefully, this work will encourage helpful discourse that results in a refinement of the definition of AD, ultimately improving the AD-related QoL of individuals with SCI.

4.2. Strengths and limitations

In addition to the strengths and limitations mentioned in Chapter 2, there are other strengths and limitations which will be addressed in this section.

Both projects in this study were conducted according to IKT guiding principles for SCI research. The IKT guiding principles strengthened this work by improving the validity and usefulness, while avoiding tokenization.

The sample of HCPs that we interviewed are not likely representative of the entire province of British Columbia. Our sample was likely representative of the lower mainland, where there is more access to specialists and HCPs with bowel-specific training. The recruitment of this study was also limited, as all recruitment efforts to interview a general practitioner were not successful within the interview period (1 year). This could be due to the current state of the healthcare system in British Columbia; there are not enough general practitioners to serve the population, limiting their time to participate in research. It could also be due to disinterest in participating in an interview which discussed the way they performed their HCP role. This limitation could influence the broader interpretation of our results. Of note, we did interview two US HCPs and their perspectives may help us better understand whether there is broader applicability of our results.

Lastly, Chapter 3 has limited application as we are not able to offer a clear, evidence-based option for an amendment to the definition of AD. Despite not providing a simple solution, we hope the thoughts presented serve as a starting point for future consideration.

4.3. Future directions

This work underscores the need for further research to design and implement the most effective behaviour change intervention(s) to improve bowel care after SCI. An intervention analysis can now be completed to determine which intervention should be pursued to change the behaviour of HCPs having conversations about bowel care with their patients. This analysis will ensure the intervention function(s) are affordable, practicable, effective/cost-effective, acceptable, with minimal side-effects/safety concerns, and equitable, and will identify policy categories that will support systemic implementation of the chosen behaviour change intervention functions (Michie et al., 2014). Hopefully these interventions will encourage conversations about changing problematic bowel care and improve the bowel-related quality of life of individuals with SCI.

This work contributes to the discourse surrounding how AD is defined. Future research is necessary to understand the most helpful definition of AD for individuals with SCI, clinicians, and researchers. Ideally, an international consensus statement regarding the definition of AD could be co-produced by all stakeholders, hopefully allowing for the refinement of the definition.

This work benefits from the use of the IKT guiding principles, and emphasizes the importance of engagement through the research process with each level of stakeholder. I hope future research continues to follow the IKT guiding principles.

4.4. Final thoughts

This work could help empower individuals with SCI to enhance their bowel care routines by ensuring the current understanding of best-practises is effectively translated between HCPs and individuals with SCI, resulting in greater independence and alleviating the detrimental impact of bowel care on quality of life (Lucci et al., 2020; Piatt et al., 2016). It will also spark conversations about the definition of AD that could lead to more sensitive diagnosis and faster treatment for this dangerous and uncomfortable condition. Collectively, this work will improve bowel care and quality of life for people living with SCI.

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Appendix A.

Integrated Knowledge Translation Guiding Principles for SCI Research

To engage meaningfully in research that is relevant, useful and/or useable, the IKT guiding principles are:

1) Partners develop and maintain relationships based on trust, respect, dignity, and transparency.

2) Partners share in decision-making.

3) Partners foster open, honest, and responsive communication.

4) Partners recognize, value, and share their diverse expertise and knowledge.

5) Partners are flexible and receptive in tailoring the research approach to match the aims and context of the project.

6) Partners can meaningfully benefit by participating in the partnership.

7) Partners address ethical considerations.

8) Partners respect the practical considerations and financial constraints of all partners.

List D1. Integrated knowledge translation (IKT) guiding principles for conducting and disseminating spinal cord injury research in partnership. Used with permission from Gainforth, H. L., Hoekstra, F., McKay, R., McBride, C. B., Sweet, S. N., Ginis, K. A. M., ... & Willms, R. (2021). Integrated knowledge translation guiding principles for conducting and disseminating spinal cord injury research in partnership. Archives of Physical Medicine and Rehabilitation, 102(4), 656-663.

Appendix B.

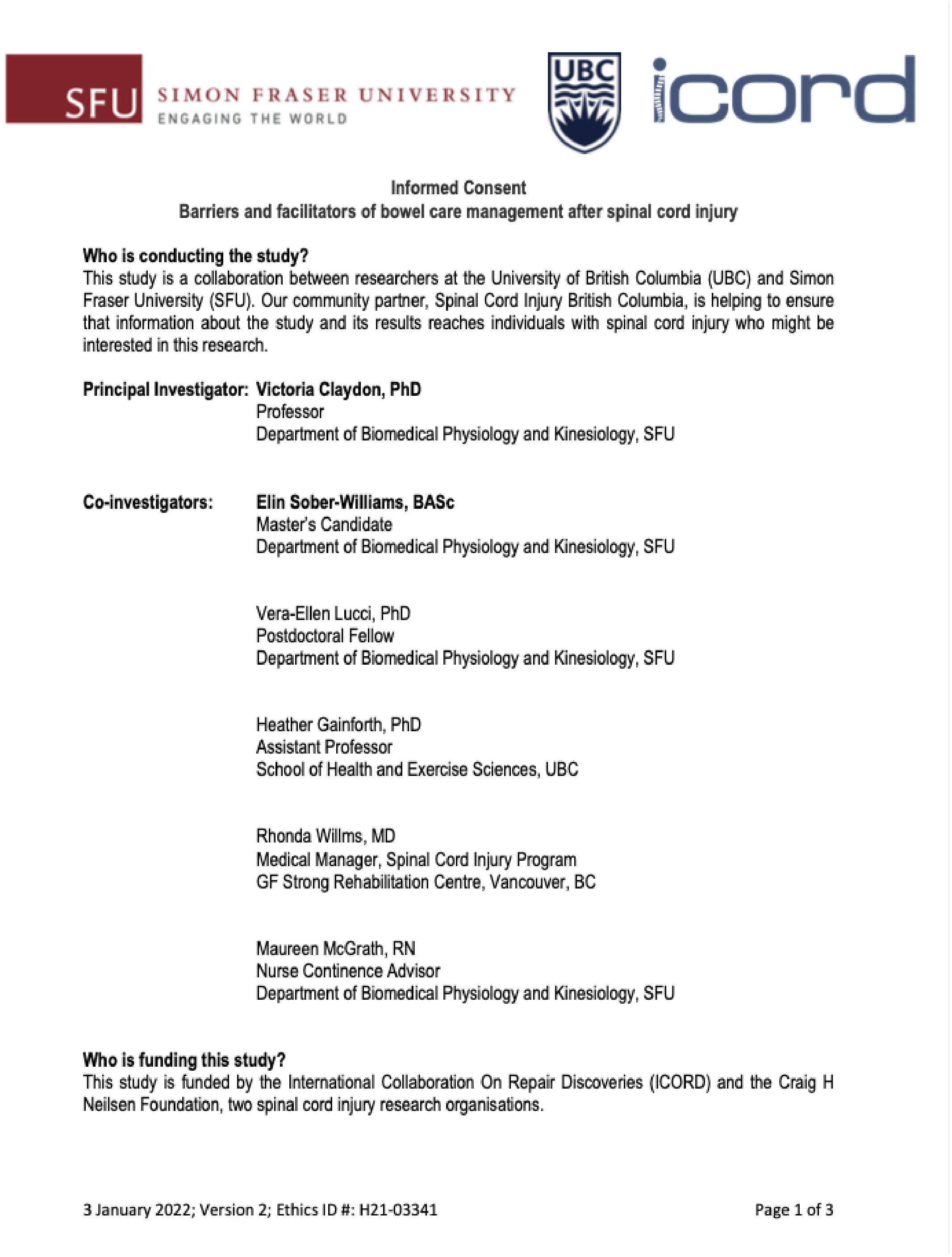
Integrated Knowledge Translation Process

Table B1. Integrated Knowledge Translation Process.

Research Stage	Consultation Medium	Description of Partnership
Identification of knowledge partners	Discussion (video call)	Guided by the integrated knowledge translation guiding principles for research in the SCI community, and due to the location of the study (within British Columbia), we included research end-users as partners in the study process throughout. These partners included a community partner, Spinal Cord Injury British Columbia (SCI BC) (CMB), and local SCI clinicians (RW, MM). Description of community partner: For more than 60 years, SCI BC has been helping individuals with SCI living in British Columbia to adapt, adjust and thrive, and is British Columbia's preeminent organization for peer support and information about living well with an SCI. SCI BC has a provincial membership of >2,500 individuals and has a long-standing history of partnering with academic researchers. They regularly communicate with more than 4,000 people, including individuals with SCI, family members and caregivers, health professionals, and other community and provincial stakeholders.
Conceptual design	Discussion (video call)	The research question and methodology were developed in partnership with the broader team including EKSW, VEL, VEC, HG, RW, MM, and CMB.
Conceptual design	Discussion (video call)	EKSW, VEL, VEC, HG, CMB, MM, and RW finalized methodology decisions including recruitment goals, interview guide, and data analysis plan.
Recruitment	Discussion (video call)	EKSW adapted templates for recruitment posters, social media recruitment, and consent forms that VEL had previously created. All materials were reviewed and edited by VEC. HG, RW, MM, and CMB reviewed, edited and approved recruitment materials and procedures. Once approved, EKSW distributed recruitment materials.
Data collection	E-mail correspondence	EKSW scheduled and recorded all 13 interviews.
Data analysis, interpretation, and dissemination	Discussion (video call)	Guided by the Theoretical Domains Framework, ESKW and VEL deductively coded interview transcripts. EKSW and VEL presented initial coding to VEC and HG, who made recommendations to refine the coding approach. EKSW conducted the inductive analysis and refined themes with VEL, HG, and VEC. EKSW presented the results of deductive and inductive coding to CMB, RW, HG, VEC, VEL, and MM where all discussed the interpretation of the results. EKSW will present the findings to SCI BC (with VEC and CMB also present) and discuss the resonance of findings with SCI BC members external to the research team. EKSW prepared the presentation of findings that was reviewed by VEL and VEC.
Manuscript preparation	E-mail correspondence	VEC and EKSW wrote the first draft of the manuscript. All co-authors reviewed the manuscript, provided feedback, and approved the final content prior to submission for publication.

Appendix C.

Study Materials



Informed Consent
Barriers and facilitators of bowel care management after spinal cord injury

Who is conducting the study?
This study is a collaboration between researchers at the University of British Columbia (UBC) and Simon Fraser University (SFU). Our community partner, Spinal Cord Injury British Columbia, is helping to ensure that information about the study and its results reaches individuals with spinal cord injury who might be interested in this research.

Principal Investigator:	**Victoria Claydon, PhD** Professor Department of Biomedical Physiology and Kinesiology, SFU
Co-investigators:	**Elin Sober-Williams, BASc** Master's Candidate Department of Biomedical Physiology and Kinesiology, SFU
	Vera-Ellen Lucci, PhD Postdoctoral Fellow Department of Biomedical Physiology and Kinesiology, SFU
	Heather Gainforth, PhD Assistant Professor School of Health and Exercise Sciences, UBC
	Rhonda Willms, MD Medical Manager, Spinal Cord Injury Program GF Strong Rehabilitation Centre, Vancouver, BC
	Maureen McGrath, RN Nurse Continence Advisor Department of Biomedical Physiology and Kinesiology, SFU

Who is funding this study?
This study is funded by the International Collaboration On Repair Discoveries (ICORD) and the Craig H Neilsen Foundation, two spinal cord injury research organisations.

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Why are we doing this study?
The purpose of this study is to investigate what helps and what hinders individuals in making changes to their bowel care routines. Research shows that the majority of individuals with SCI do not change their bowel care routines despite being unhappy with them. We are interested in the reasons why some people have made changes to their care and why others have not. We started to address this by interviewing people with SCI to find out their perspectives on their care. We will now build on that research by interviewing the healthcare providers of people with SCI to find out their perspectives on what might help or hinder changing bowel care practices.

How is this study done?
You are eligible to take part in the study if you are at least 19 years old, are a healthcare provider, and are comfortable communicating in English. For this study, you will first complete an online screening tool that will help us determine your eligibility for the study. Not everyone who completes the screening tool will be able to complete the study. We will select individuals so that we have representation from people with a range of experiences in treating spinal cord injury, with balanced representation of sex/gender, a range of ages, and those practicing in the city as well as in rural areas. If you are selected, a member of the research team will then contact you to schedule an interview at a time that works for you, where we will ask your opinions about your patients' bowel care. Interviews will be conducted by telephone or online through Zoom, depending on participant preference. At the time of the interview, you will be asked to verbally consent to the interview being audio-recorded by a member of the research team. You can choose not to be recorded, but if you do you will not be able to continue the study. The interview will be one-on-one over the phone or online and will take approximately 60 minutes. When signing onto Zoom you should use a research code that will be given to you ahead of time. You are welcome to turn the camera off and can mute the microphone any time when you are not speaking. Questions in the interview will focus on your experience with prescribing bowel care routines, reasons why you may or may not have made changes to patient bowel care routines, and what the biggest challenges are to making changes to patient bowel care routines. Questions might include "if you have a patient with a spinal cord injury and are prescribing a bowel care routine, what do you typically prescribe?". If you like, you can have a chance to see example questions ahead of time.

Are there risks to participating in this study?
It is not likely that there will be any serious harms or discomforts associated with the interview. There are no known physical, psychological, economic or social risks associated with this study. Some people may feel uncomfortable talking about prescribing bowel care. You are not obliged to answer any questions or participate in anything that you find embarrassing or that makes you feel uncomfortable. You can tell us if you would like to skip a question. You may also withdraw from the study at any time. You do not need to give a reason if you decide to stop the study.

What are the benefits of participating in this study?
It is unlikely that there will be direct benefits to you, however, your participation in this study will help to inform future investigations into bowel care and management. By participating in this research, participants can contribute to prioritizing research and guiding resources to areas that are most relevant to those with an SCI and that may be more likely to bring about positive outcomes for this population.

Will you be paid for taking part in this study?
There will be no cost to you for participating in the study. You will be paid $20 for your participation in this study as compensation for your time. This payment will be in a gift card of your choosing.

How will your privacy be maintained?

The screening tool is administered by an online survey through SurveyMonkey. All data will be stored and backed up in Canada. Data will be kept for ten years. If you complete the interviews, your interview will be recorded. It is possible that the audio-recordings will contain identifiable information, particularly if you share personal details (your name or where you live). A copy of the recording will be housed on a secure university server for up to ten years in case we need to refer back to them. The interviews will also be transcribed word-for-word and de-identified (no names or personal details e.g. address or place of work) so we can explore the issues you raise without you being identified. Electronic recordings, survey, and transcription data will be stored on password-protected computers. Research findings will be published in online and printed community publications, professional journals, presented at scientific conferences, and published in the Master's thesis of research investigator Ms. Elin Sober-Williams, but any presentations will be of general findings only e.g. responses combined from all participants or, if we use an individual quote, will be presented in a way that makes it very unlikely that anyone could tell who the quote came from (no personal details e.g. where you live or what your name is would be given). Any data you provide may be transmitted and stored in countries outside of Canada, as well as in Canada. It is important to remember that privacy laws vary in different countries and may not be the same as in Canada.

What If I decide to withdraw my consent to participate?

Your participation in this research study is entirely voluntary and therefore it is up to you to decide whether or not to participate in this study. Before you decide, it is important that you understand what the research involves. This informed consent form details why the research is being done, what will happen to you during the study, and the possible risks and benefits to participating in the study. You are under no obligation to participate in this study.

Who can you contact if you have questions about the study?

Please ask the study investigators, Dr. Victoria Claydon, or Ms. Elin Sober-Williams for clarification where needed. Research results for this study can be obtained upon request from Dr. Claydon at the address given above, by e-mail

Who can you contact if you have complaints or concerns about the study?

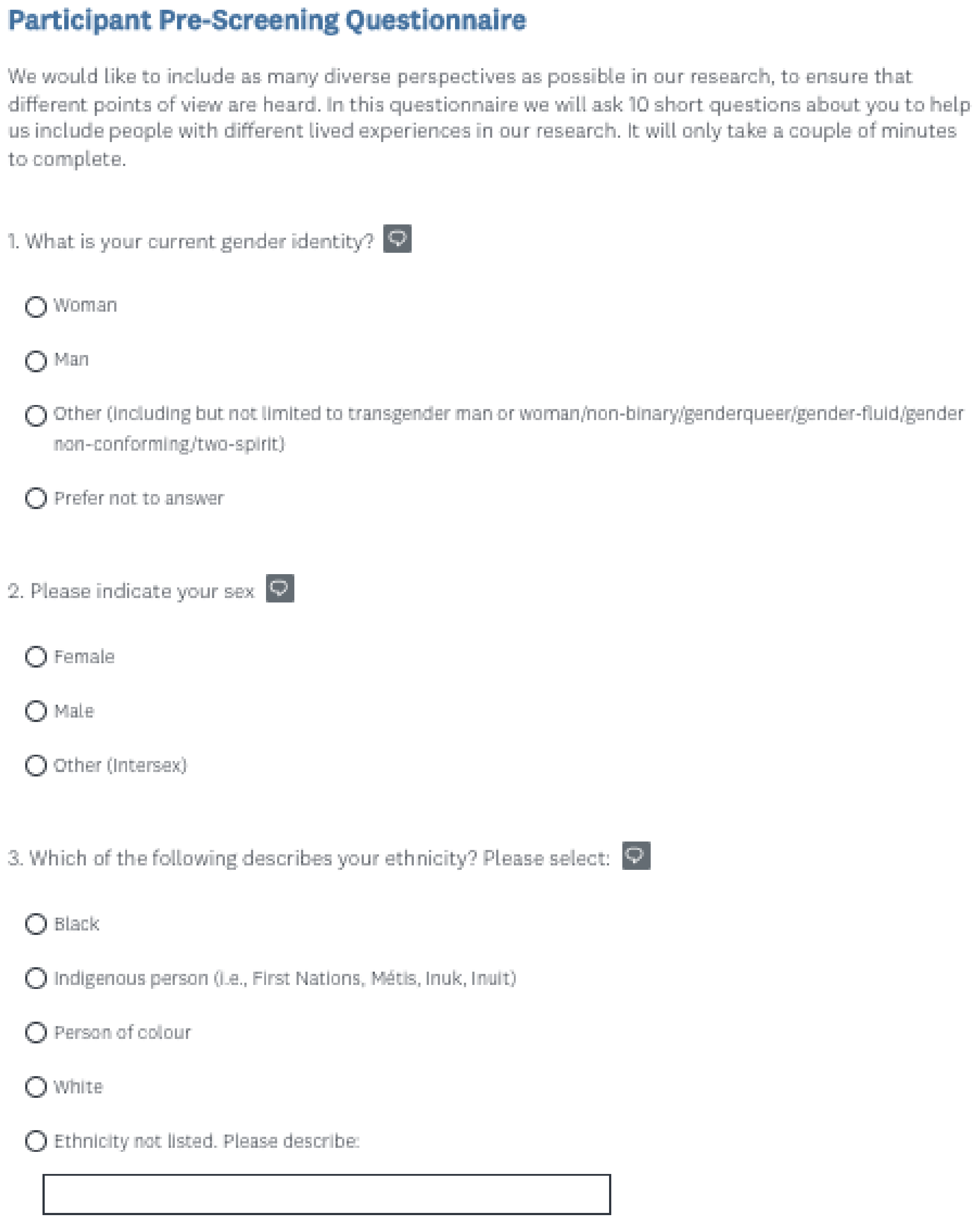
If you have any concerns about your rights as a research participant and/or your experiences while participating in this study, you may contact the SFU Office of Research Ethics

Consent

Your participation is entirely voluntary. You can decide to stop at any time, even part-way through the interview, for whatever reason. If you decide to stop participating, there will be no consequences to you and we will not ask for a reason. We can discuss what you would like to be done with your data if you decide to stop. This could include returning it to you, destroying it, or using the data collected up to that point. If you have any questions or would like further information about this study, you may contact Dr. Victoria Claydon

If you would like to participate, please click on the "next page" button to begin. This will indicate you have read and understood the above information and have consented to participate in this study. By clicking "next page" you will be directed to a screening tool that will determine your eligibility for the study. If you do not wish to participate, please exit this website.

Please print or save a copy of this form for your records



Participant Pre-Screening Questionnaire

We would like to include as many diverse perspectives as possible in our research, to ensure that different points of view are heard. In this questionnaire we will ask 10 short questions about you to help us include people with different lived experiences in our research. It will only take a couple of minutes to complete.

1. What is your current gender identity?

○ Woman

○ Man

○ Other (including but not limited to transgender man or woman/non-binary/genderqueer/gender-fluid/gender non-conforming/two-spirit)

○ Prefer not to answer

2. Please indicate your sex

○ Female

○ Male

○ Other (Intersex)

3. Which of the following describes your ethnicity? Please select:

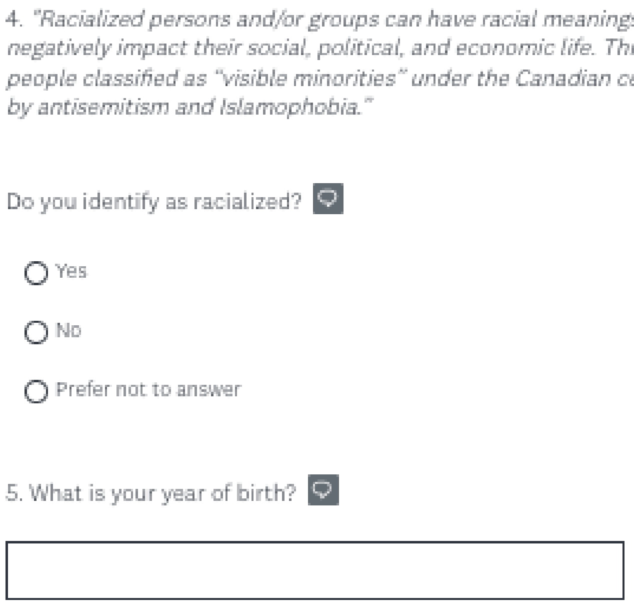
○ Black

○ Indigenous person (i.e., First Nations, Métis, Inuk, Inuit)

○ Person of colour

○ White

○ Ethnicity not listed. Please describe:



4. *"Racialized persons and/or groups can have racial meanings attributed to them in ways that negatively impact their social, political, and economic life. This includes but is not necessarily limited to people classified as "visible minorities" under the Canadian census and may include people impacted by antisemitism and Islamophobia."*

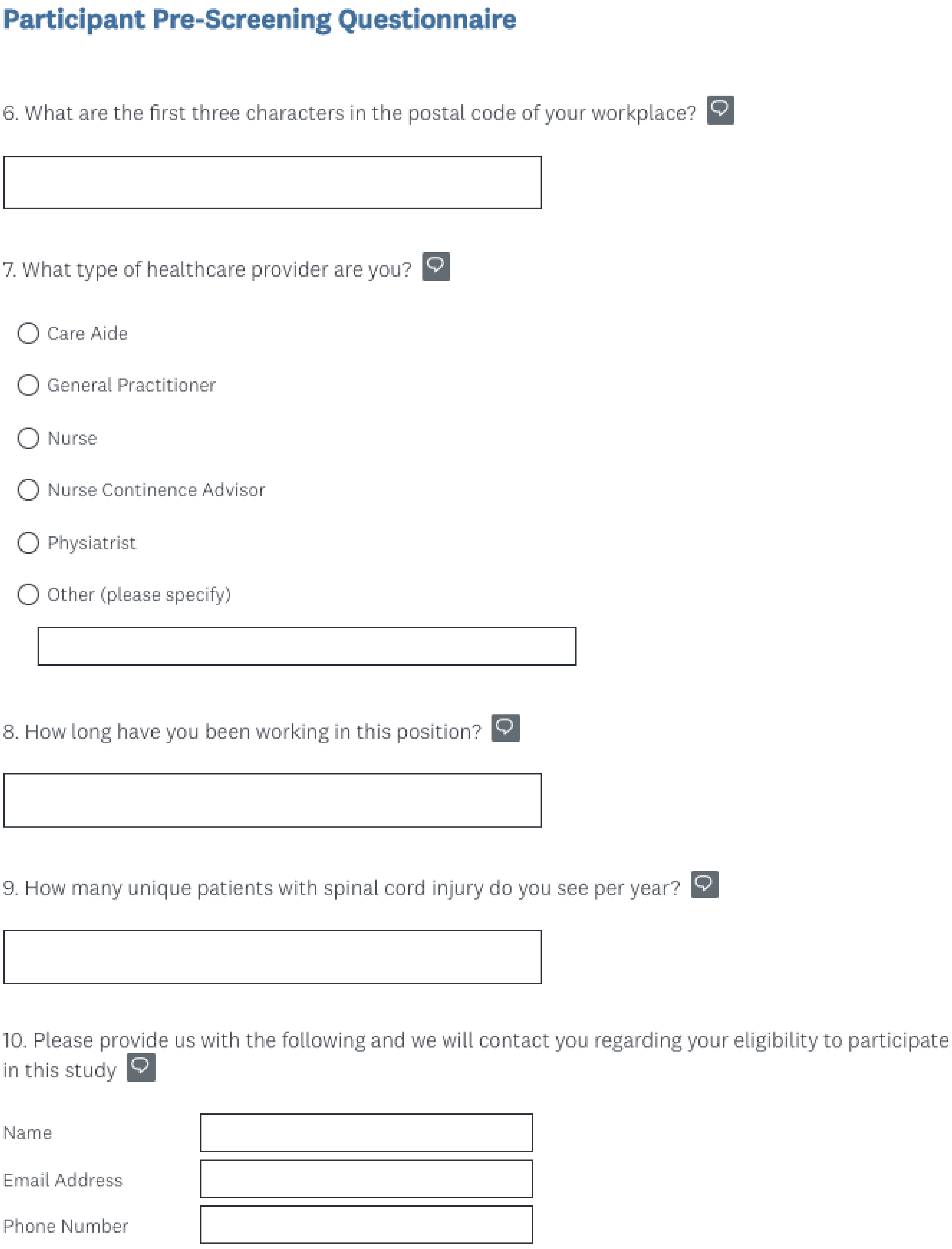
Do you identify as racialized?

○ Yes

○ No

○ Prefer not to answer

5. What is your year of birth?



Participant Pre-Screening Questionnaire

6. What are the first three characters in the postal code of your workplace?

7. What type of healthcare provider are you?

○ Care Aide

○ General Practitioner

○ Nurse

○ Nurse Continence Advisor

○ Physiatrist

○ Other (please specify)

8. How long have you been working in this position?

9. How many unique patients with spinal cord injury do you see per year?

10. Please provide us with the following and we will contact you regarding your eligibility to participate in this study

Name

Email Address

Phone Number

HELP US UNDERSTAND WHY YOUR PATIENTS AREN'T MAKING HEALTH CHANGES

HEALTH CARE PROFESSIONALS NEEDED FOR INTERVIEW STUDY:

BARRIERS & FACILITATORS OF BOWEL CARE MANAGEMENT AFTER SPINAL CORD INJURY

We are currently recruiting medical professionals to discuss bowel care routines of individuals with spinal cord injury and what makes changing them difficult. The purpose of this study is to investigate what helps and what hinders individuals in deciding to make changes to their bowel care routines. If you choose to participate in this study, you will fill out an online screening tool that will determine if you are eligible to be in the study (takes about 5 minutes). You would then talk with one of the researchers at a time that is convenient to you about your thoughts on bowel care. This conversation will be up to 60-minutes long.

To take part in this study you must:
- Be a medical professional
- Be over the age of 18
- Speak English

Participants will receive a $20 gift card to a store of your choice for completing the interview.

If you are interested in participating, please follow this QR code to learn more and complete the screening tool:

If you have any questions about the study, please email Ms. Elin Sober-Williams at [redacted] or Dr. Victoria Claydon at [redacted] or call the lab at [redacted]

Version: 1 Date: December 8th 2021

Interview Guide

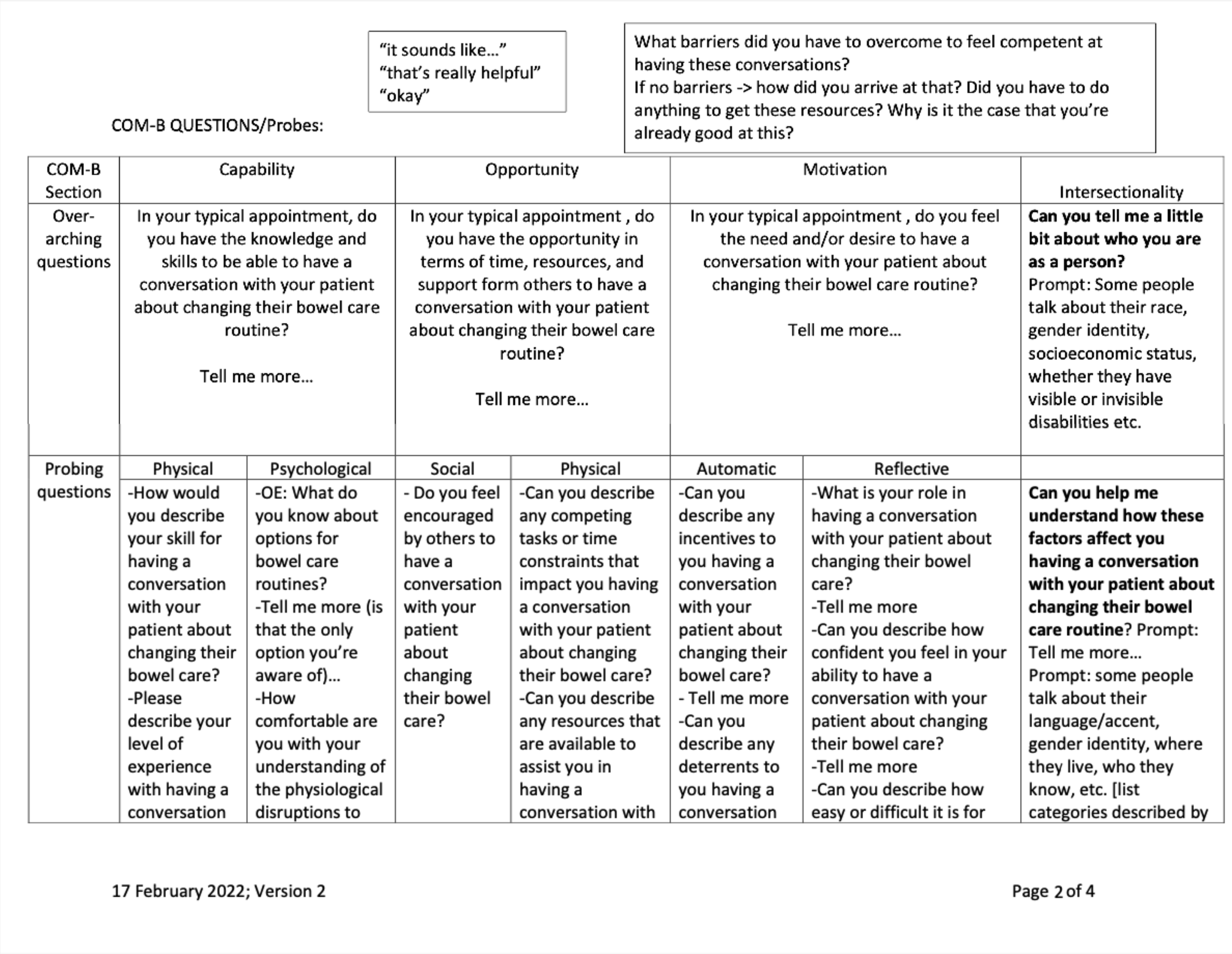
CONSENT & PURPOSE:
Please confirm that you consent to have our conversation recorded.

Your personal information has been assigned the random ID number ________. To insure confidentiality and anonymity this data will be stored under the same number in a secure, password-protected location inside our locked laboratory. I will not use your name as we are talking to help protect your confidentiality. You can withdraw at any point. Please keep in mind that there are no right or wrong answers to these questions.

We are asking these questions in a **non-judgemental** space. The goal is simply to figure out what resources, if any, would be of use to people caring for individuals with SCI in the context of bowel care, not to evaluate the quality of care provided.

INTRODUCTORY QUESTIONS:

- How do (or do you) typically have conversations with your patients about their bowel care routines?
    - What is your current practice?
    - What do you think the best practices should be?
    - What do you think the worst practices would be?
- What would stop you from having a conversation with a patient about their bowel care routine (i.e following best practices)?
- What would help you have a conversation with a patient about their bowel care routine?
- What do you think is a priority for bowel care from a medical perspective? Do you think the patient prioritizes the same concern?
- What factors do you consider when evaluating bowel care? (physiology, age, patient satisfaction, sex, concurrent bladder and sexual function, patient environment, resources, ability, peer mentorship)
- Do you make recommendations/prescribe changes to bowel care routines? If not, why?
- If you have made a suggestion (s), do you follow up on their bowel care routines? If not, why?



"it sounds like…"
"that's really helpful"
"okay"

What barriers did you have to overcome to feel competent at having these conversations?
If no barriers -> how did you arrive at that? Did you have to do anything to get these resources? Why is it the case that you're already good at this?

COM-B QUESTIONS/Probes:

COM-B Section	Capability		Opportunity		Motivation		Intersectionality
Over-arching questions	In your typical appointment, do you have the knowledge and skills to be able to have a conversation with your patient about changing their bowel care routine? Tell me more…		In your typical appointment , do you have the opportunity in terms of time, resources, and support form others to have a conversation with your patient about changing their bowel care routine? Tell me more…		In your typical appointment , do you feel the need and/or desire to have a conversation with your patient about changing their bowel care routine? Tell me more…		**Can you tell me a little bit about who you are as a person?** Prompt: Some people talk about their race, gender identity, socioeconomic status, whether they have visible or invisible disabilities etc.
Probing questions	Physical	Psychological	Social	Physical	Automatic	Reflective	
	-How would you describe your skill for having a conversation with your patient about changing their bowel care? -Please describe your level of experience with having a conversation	-OE: What do you know about options for bowel care routines? -Tell me more (is that the only option you're aware of)… -How comfortable are you with your understanding of the physiological disruptions to	- Do you feel encouraged by others to have a conversation with your patient about changing their bowel care?	-Can you describe any competing tasks or time constraints that impact you having a conversation with your patient about changing their bowel care? -Can you describe any resources that are available to assist you in having a conversation with	-Can you describe any incentives to you having a conversation with your patient about changing their bowel care? - Tell me more -Can you describe any deterrents to you having a conversation	-What is your role in having a conversation with your patient about changing their bowel care? -Tell me more -Can you describe how confident you feel in your ability to have a conversation with your patient about changing their bowel care? -Tell me more -Can you describe how easy or difficult it is for	**Can you help me understand how these factors affect you having a conversation with your patient about changing their bowel care routine**? Prompt: Tell me more… Prompt: some people talk about their language/accent, gender identity, where they live, who they know, etc. [list categories described by

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	with your patient about changing their bowel care. -Tell me more -Can you tell me about a time when you wanted to have a conversation with your patient about bowel care but couldn't or didn't?	the bowel after spinal cord injury and how they might influence bowel care options? -Tell me more -How do you normally have a conversation with your patient about prescribing bowel care? -Is having a conversation about your patients' bowel care something you remember to do?		your patient about changing their bowel care? -Tell me more -How do you look for information to support your having a conversation with your patient about changing their bowel care? -How important is it to include discussion of support available from care aides/family members in conversations about bowel care? -Tell me more	with your patient about changing their bowel care? - Tell me more -What steps do you take to insure you have a conversation about bowel care with patients? -Tell me more - Can you describe how comfortable are you discussing bowel care with patients? -If your conversation revealed the need to change bowel care how comfortable are you with prescribing a change?	you to have a conversation with your patient about changing their bowel care? -Tell me more - Can you describe the positive or negative outcomes you think will occur when you have a conversation about bowel care with your patient? (What costs or benefits do you predict/perceive) -Tell me more -Can you describe your motivation to have a conversation with your patient about changing their bowel care? -Can you describe how intentional you are/are not about having a conversation with your patient about changing their bowel care? -Tell me more -Among your priorities, how would you consider having a conversation with your patient about	respondent] **Are there [other] social identity categories that you have observed as important for conversations between patients and caregivers about changing their bowel care?** Prompt: Tell me more… **Do you think your patients' intersecting categories influence conversations about changing their bowel care?** Tell me more…

					-Tell me more	changing their bowel care? -Tell me more -When discussing bowel care with a patient what is your goal outcome? -Tell me more (is your goal continence, effective evacuation, time to complete, AD severity, independence in bowel care, etc)	

Follow-up questions:

- How would you like to receive information about bowel care?
  - Who would you like to receive this information from? (Peers, Organizations, health authorities, etc.)
  - What formats would work? Face to face/pamphlet/online etc.?

Would you like to see a summary of the study results when it is finished?

That's all the questions I have for you, is there anything else that you would like to touch on?

I will send you an email with details about how you can claim your gift card.