DEVELOPING RECOMMENDATIONS FOR INTERVENTIONS THAT SUPPORT INDIVIDUALS AGING WITH SPINAL CORD INJURY

by

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Abstract

Introduction: Although the life expectancy of people living with spinal cord injury (SCI) is increasing, efforts to understand successful aging (SA) continue to exclude those with long-term physical disabilities. Participation may be an ideal target behaviour for interventions, as evidence suggests participation is related to health, well-being, and life satisfaction. Theory provides a systematic approach to intervention development that may improve effectiveness and replicability. Additionally, use of integrated knowledge translation (IKT) may improve likelihood that findings will be relevant and useful to target populations.

Objective: The purpose of this thesis was to work in partnership with SCI organizations to co-develop theory-based recommendations for interventions designed to enhance participation while aging with SCI. Accordingly, this thesis used an IKT approach to explore meanings of SA, identify barriers and facilitators to participation, and understand effective ways to deliver interventions.

Methods: Semi-structured interviews were conducted with 22 people aging with SCI and transcribed verbatim. Abductive analyses addressed all three stages of intervention development. To understand the behaviour, inductive thematic analysis and deductive coding of barriers and facilitators using the Theoretical Domains Framework (TDF) was used. To identify intervention options, a behavioural analysis was conducted using the Behaviour Change Wheel (BCW). To identify content and implementation options, intervention messengers were extracted and deductive coding of modes of delivery was conducted using the mode of delivery taxonomy (MoDtv0). All findings were synthesized in partnership into intervention recommendations, and feasibility of implementation was assessed using the APEASE criteria.

Results: Three themes were developed to understand meanings of SA with respect to definitions, barriers, and facilitators. Environmental context and resources, skills, and social influences were identified as relevant TDF domains to barriers and facilitators of participation. Six intervention functions and all policy categories were considered relevant to intervention design and implementation. Multiple messengers and modes of delivery were considered important for effectively delivering interventions. Through synthesis of all findings, four recommendations were co-developed and met APEASE criteria.

Conclusions: These findings suggest that a variety of interventions will be needed to support people aging with SCI. Future efforts are needed to implement the recommendations to develop real-world interventions.

Lay Summary

With the increase in life expectancy for people with SCI being relatively recent, programs designed specifically to support people aging with long-term spinal cord injury (SCI) have yet to be developed. This thesis aimed to develop recommendations for resources, tools, or programs that can support people aging with SCI. Twenty-two people aging with SCI were interviewed to inform the development of these recommendations. In partnership with SCI organizations, findings from the interviews were used to develop recommendations that aim to ensure people with SCI fully participate in society as they age. Findings from this thesis suggest that a variety of resources, tools, or programs will be needed to support people aging with SCI. In order for SCI organizations to use the recommendations from this thesis, a webinar and written report will be developed and distributed across each of the SCI organizations.

Preface

All study procedures for this thesis received ethics approval through the Behavioural Research Ethics Board at the University of British Columbia, Okanagan Campus (#H17-02426) (See Appendix C). Emily Giroux, Dr. Heather Gainforth, Sheila Casemore, Teren Clarke, and Dr. Chris McBride were responsible for identification of the research question and design of the study. Emily Giroux was responsible for development of recruitment materials, development of the interview guide, conducting all interviews, transcription of interviews, analysis of interview transcripts, and writing the thesis document. Dr. Gainforth supervised Emily throughout the research process, and provided intellectual input and feedback throughout the development of the interview guide, analysis of interview transcripts, and writing the thesis document. Sheila Casemore (Spinal Cord Injury Ontario), Teren Clarke (Spinal Cord Injury Alberta), Dr. Chris McBride (Spinal Cord Injury BC) and their staff recruited all participants for this study, and worked in partnership with Emily and Dr. Gainforth on recommendation development. Veronica Allan assisted with development of the interview guide and review of writing drafts of the thesis document. Brianna Tsui, Randy Butler, and Isabelle Grant assisted with transcription of interviews. Kelsey Wuerstl was responsible for double extraction and coding of barriers and facilitators and modes of delivery during deductive analyses.

This thesis has not yet been submitted for publication.

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Dedication

For Chris Chandler.

Thank you for getting me involved in the SCI community in the first place, and turning my once a week volunteer position into a full-blown passion of mine. This is for you ☺

And Amy Grenon☺ (#matzoball…you'll understand)

1 Introduction

1.1 Changing Demographic of Spinal Cord Injury

The moment a spinal cord injury (SCI) occurs, an individual's life trajectory is immediately changed. SCI can be defined as "damage to the spinal cord caused by disease or trauma resulting in partial or complete paralysis" (Rick Hansen Institute, 2017a). Individuals who live with or acquire a SCI experience physiological, psychological, and social changes that can lead to numerous negative impacts on one's overall well-being, quality of life, and participation in society (National Spinal Cord Injury Statistical Center, 2016; Rick Hansen Institute, 2017b; Simpson, Eng, Hsieh, Wolfe, & Spinal Cord Injury Rehabilitation Evidence (SCIRE) Research Team, 2012).

The Rick Hansen Spinal Cord Injury Registry (RHSCIR) (Rick Hansen Institute, 2017b), the most recent record of Canadians who have sustained a traumatic SCI, indicated that approximately 86,000 Canadians were living with SCI in the year 2004 (Noonan, Kwon, et al., 2012). The RHSCIR indicated this number was expected to increase to 121,000 Canadians by the year 2030, suggesting a 40% increase in the SCI population over a 30-year period. The continuous increase in the number of individuals living with SCI can be attributed to an increase in both the survival rate and life expectancy of people with SCI. Post World War II, people who had just acquired a SCI were rarely treated as survival beyond 12-18 months post-injury was extremely rare (Samsa, Patrick, & Feussner, 1993). Advancements in injury rehabilitation, assistive technology devices, and co-morbidity identification and treatment have contributed to a 2000% increase in survival rate after SCI (Kemp & Mosqueda, 2004), and an increase in life expectancy that has been approaching towards that of the general population (Eisenberg & Saltz, 1991). Noonan et al. (2012) found that approximately 30-40% of Canadians living with a SCI are over the age of 65, suggesting that for the first time in history, more Canadians with a SCI will be living

into their elderly years than ever before. Further understanding of the complex interactions between aging and SCI is required to ensure additional years of life are lived with meaning and quality.

1.2 Aging with a Spinal Cord Injury

Independent of SCI, aging can be viewed as a complex interaction between numerous factors including genetics, changes in daily roles and responsibilities, lifestyle choices, changes in social structures, and the potential of economic depletion (Capoor & Stein, 2005). Sixty-five years of age has been adopted as the beginning point of elderly years and "old age" across numerous developed countries worldwide (Kowal & Dowd, 2001). Conversely, physiological signs of aging into elderly years for people living with SCI have become evident as early as forty-five years of age (Krause & Coker, 2006), due to a range of factors that include, but are not limited to, the formation of pressure ulcers and an increased risk of various conditions including obesity, cardiovascular disease, and respiratory disorders (Charlifue, Jha, & Lammertse, 2010; El-Masry & Haboubi, 2001; Post & Reinhardt, 2015). The complex interaction that occurs between a SCI and biological aging is not well-understood, as difficulty arises when attempting to establish if the underlying cause of an outcome is attributed to the SCI, the aging process, or a combination of the two.

Research on aging with SCI has primarily focused on resulting physiological outcomes and associated co-morbidities (Fougeyrollas & Noreau, 2000). Hitzig et al. (2011) conducted a systematic review of 74 studies on the impact that aging with SCI has on various body systems. Findings from the review indicated that varying degrees of premature aging occur only in some body systems after SCI including the cardiovascular, endocrine, musculoskeletal, immune, and respiratory systems. However, the review was unable to make definitive conclusions as further

research was required to confirm findings. Across the literature, pressure sores, urinary tract infections, cardiovascular disease, and respiratory disease have been identified as the most prominent secondary conditions responsible for morbidity in people living with SCI (Adkins, 2004; Whiteneck et al., 1992). McColl et al. (2002) described five changes that individuals living with SCI undergo as they age: [1] effects of living with a SCI for many years (e.g. shoulder deterioration, chronic bladder infections, postural problems), [2] secondary complications of the original lesion (e.g. post-traumatic syringomyelia), [3] pathological complications unrelated to the SCI (e.g. heart disease), [4] aging-related degenerative changes (e.g. joint and sensory problems), and [5] environmental factors (e.g. societal, community, and cultural issues). Of these five changes, four are specific to physiological changes with aging, with only one being specific to societal and cultural changes. Despite this progress, the investigation of vital components of the relationship between aging and SCI, such as social changes specific to aging with SCI, remain relatively uninvestigated. Further understanding of social outcomes is required to be able to develop and implement supports for individuals aging with SCI (Mortensen et al., 2014).

1.3 Social Outcomes, Aging, and Spinal Cord Injury

The prioritization of improved social outcomes is a fundamental goal of SCI rehabilitation. Previously, changes in social outcomes after SCI, regardless of age group, were rarely evaluated in the literature (Fougeyrollas & Noreau, 2000; Post & van Leeuwen, 2012). In the context of disability research, a social outcome is broadly defined as an intended result of a designed intervention that is directly related to a change in social function (e.g. daily roles and responsibilities, interpersonal relationships) (Dijkers, Whiteneck, & El-Jaroudi, 2000). Social outcomes are described in a heterogeneous manner, with terms being used interchangeably across the literature. For example, social outcomes are frequently characterized as one of the following:

participation, social participation, community participation, quality of life, well-being, successful aging, and life satisfaction (Barclay, McDonald, & Lentin, 2015; Yorkston, McMullan, Molton, & Jensen, 2010). Reviews of the literature have been conducted to synthesize definitions of various social outcomes associated with aging (Cosco, Prina, Perales, Stephan, & Brayne, 2014; Depp & Jeste, 2006; Levasseur, Richard, Gauvin, & Raymond, 2010). However, these reviews were specific to aging in the general population and reviews specific to aging with long-term physical disabilities have yet to be conducted. Research that examines how we can support people with SCI to thrive socially while aging is urgently needed, as anxiety towards aging has been identified and addressed as a long-standing issue for the SCI population (McColl, Stirling, Walker, Corey, & Wilkins, 1999).

1.4 Models and Frameworks of Successful Aging

As the global trend of population aging continues to rapidly grow, the primary focus of gerontology literature has shifted towards the development of strategies that support aging among the general population. Rich, theoretical concepts that have been used to support aging in the general population may show promise as an approach to provide support to individuals aging with SCI (Bombardier, Ehde, Stoelb, & Molton, 2010). The development of the construct *successful aging* has gained popularity as the second most commonly used concept across gerontology literature, only falling second to stress models (Alley, Putney, Rice, & Bengtson, 2010). Successful aging can be broadly defined as the enhancement or maintenance of physical, mental, and social well-being with age. The development of successful aging models has allowed for the process of aging in the general population to be understood from a variety of different perspectives (e.g. physical, mental, social, spiritual, financial). The most commonly cited successful aging frameworks take on the form of prevention models (Holstein & Minkler, 2003). For example,

Rowe and Kahn's (1997) Model of Successful Aging states that for one to successfully age, all three of the following criteria must be achieved: [1] avoidance of disease or disease-related disability, [2] maintenance of a high cognitive and physical functional capacity, and [3] ability to remain actively engaged with life.

Prevention models like Rowe and Kahn's exclude people living with SCI, as these individuals are already living with a physical disability and decreased functional capacity. Social gerontologists have recommended that more realistic and inclusive models for successful aging need to be developed (Martinson & Berridge, 2015; Pruchno, Wilson-Genderson, & Cartwright, 2010; Young, Frick, & Phelan, 2009). Young et al. (2009) proposed a multi-dimensional model that integrates three domains: physiological, psychological, and social. The model implies a continuous approach that allows for successful aging to be reached, even if limitations due to chronic illness or functional limitations exists in any of the three domains. However, the model fails to take into account the perspectives of individuals with lived experience of physical disability, as the model was informed from "experts" in the field (i.e. geriatricians, epidemiologists, geriatric nurses, economists). Pruchno et al. (2010) proposed a two-fold model that encompasses subjective and objective criteria of successful aging. In the model, objective criteria are measured along the following: having few chronic diseases, ample functional ability, and little or no pain. Subjective criteria are indicated by an individual's evaluation of their own aging experience at a single point in time. However, the model recognizes the importance of acceptance of the inability to age "disability-free", indicating the exclusion of individuals with long-term disabilities. Despite these efforts, limitations still exist and individuals with physical disabilities are still being excluded from research studies which use successful aging models as a guiding framework (Molton & Yorkston, 2017).

1.5 Developing a Spinal Cord Injury Specific Framework of Successful Aging

An inclusive and SCI-specific theoretical framework of successful aging may help to inform efforts to support people with SCI as they age. In previous efforts, focus groups were conducted with individuals with a variety of physical disabilities to determine what an ideal model of successful aging should include (Molton & Yorkston, 2017; Yorkston et al., 2010). The following five themes were developed from the first focus group: [1] participant identity, [2] physical pathways, [3] psychosocial pathways, [4] changing health care, and [5] concerns about the future (Yorkston et al., 2010). In the second focus group, participants indicated that the following components should be considered in the model: [1] psychological resilience; [2] psychological adaptability and flexibility; [3] autonomy and choice in decision making; [4] social and community participation and positive connection to others, [5] accessible, appropriate and available medical care, and [6] effective compensation for functional impairments (Molton & Yorkston, 2017). Although the focus groups were inclusive of participants with disabilities other than SCI, themes developed from both focus groups somewhat align with Rowe and Kahn's (1997) concept of social well-being (i.e. an ability to remain actively engaged in life), as well as the more well-understood concept of *participation*.

Participation is defined as the nature or extent of a persons' involvement in life situations in both daily activities (e.g., going shopping) and social roles (e.g., being a parent) (World Health Organization, 2001). Participation is globally understood as a basic human right (United Nations Department of Public Information, 2006), as it plays such an important role in overall human function. Current evidence supports that full participation is directly related to successful aging, greater well-being, and improved quality of life in the general population (Desrosiers, Noreau, & Rochette, 2004). Similar evidence has been found in the SCI population as participation has been

related to improvements in physiological health, psychological health, and life satisfaction (Carpenter, Forwell, Jongbloed, & Backman, 2007; Sweet, Noreau, Leblond, & Martin Ginis, 2016).

Across disability research, participation has been continuing to emerge as a gold standard social outcome (Seekins et al., 2012). This emergence may be due to a number of factors including improved clarity around SCI-specific participation behaviours and the development of disability-specific subjective and objective measures of both the quantity and quality of participation. Noreau et al. (2013) worked with 50 members of the SCI community to develop the Person-Perceived Participation in Daily Activities Questionnaire (PDAQ), a SCI-specific measure of participation that clearly outlines 26 succinct participation behaviours (e.g. carrying out financial responsibilities, performing bowel care, maintaining your physical health, participating in activities and organizations, etc.). Not only did development of the PDAQ provide clarity around what participation behaviours specific to the SCI population may be, but it is also representative of a SCI-specific subjective measure of participation.

Martin Ginis et al. (2017) conducted a configurative review of definitions and conceptualizations of participation specific to people living with physical disabilities, with the aim of identifying experiential aspects of participation that are missed when solely quantifiable measures of participation are used. The review provides clarity across subjective measures of participation and identifies six themes to describe experiential aspects of participation: [1] autonomy, [2] belongingness, [3] challenge, [4] engagement, [5] mastery, and [6] meaning. The themes developed from the review provided a starting point for a conceptualization of the experiential aspects of participation.

Seekins et al. (2012) conducted a scoping review to evaluate the status of participation measures specific to individuals with physical disabilities. The review identified 67 distinct quantitative measures of participation that were disability-specific. Conversely, the importance of subjective measures of participation was frequently identified, yet rarely measured.

Participation shows promise as a social outcome that may be valuable to target in interventions that promote successful aging among people with SCI. Despite the strength of the relationship between participation and SCI, the addition of aging as a third variable has yet to be investigated from a perspective developed from the lived experiences of people aging with SCI. Therefore, the use of qualitative research methods is a potentially valuable approach to understand the complex relationship between participation, aging and SCI.

1.6 The Importance of Qualitative Methods in Intervention Development

Research investigating participation in individuals aging with SCI frequently uses quantitative approaches (Krause, Clark, & Saunders, 2015; Lundstrom et al., 2017; Lundstrom, Lilja, Gray, & Isaksson, 2015; Post & Reinhardt, 2015). Quantitative research methods are driven by the development of pre-determined measures by researchers, allowing for a comprehensive understanding of variables that have already been found to have a well-established relationship with one another (Hammell, 2007). Hammell (2010) indicated that future SCI research needs to move towards a direction that focuses more on issues that are important to individuals with SCI with the end goal of developing interventions. The use of qualitative methods is valuable in moving towards this new direction, as they can allow for a deeper understanding of human experiences and perspectives across a variety of contexts (Creswell, Klassen, Plano Clark & Smith, 2011).

Various researchers have outlined the importance of conducting qualitative research to understand priorities from the perspective of people living with SCI and subsequently inform the

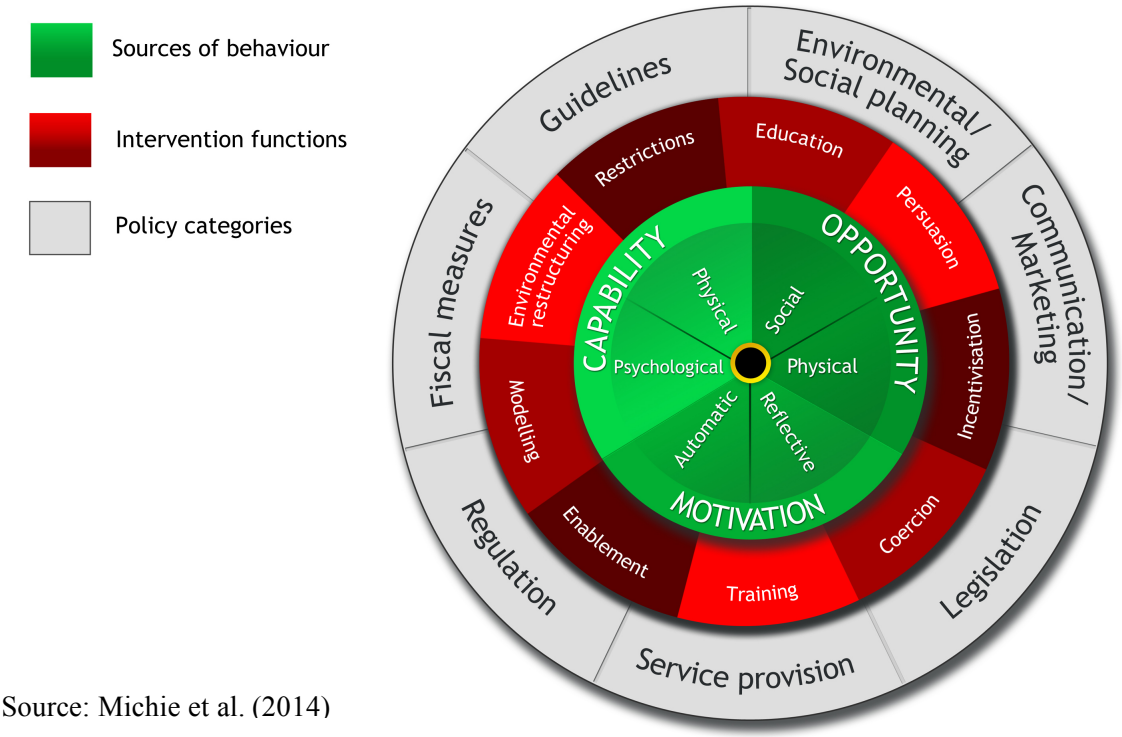
development of quantitative studies (Estores & Sipski, 2004; Hammell, 2007, 2010). Subjective experiences of aging with SCI are of importance to the development of interventions specific to the SCI population, as these experiences cannot be reliably predicted by a researcher with no first-hand experience of aging with SCI. Seekins et al. (2012) identified that although subjective experiences of SCI have been considered important across the literature, their use has rarely been reported or measured. Qualitative research methods are also particularly useful in providing a storyline to concepts where the progressive course of change is unknown (Yorkston et al., 2010). The use of interchangeable terminology between "participation", "social participation," and "community participation" across the literature may contribute to this inability to measure progressive change. Solutions to address the difficulty to measure progressive change in participation may be suggested or evolved through the use of qualitative research methods. Specifically, semi-structured interviews can provide a structured, yet flexible approach to data collection, allowing for initial information of interest to be collected in a systematic manner, while remaining flexible to allow for unpredictable themes based on personal experience, opinions, ideas, feelings, and attitudes to emerge (Creswell et al., 2011; Sparkes & Smith, 2014). As such, interventions designed to enhance participation in people living with SCI that are aging may potentially be more relevant, useful, and actually used if they are informed with the perspectives of individuals who have lived experience of aging with SCI.

1.7 The Importance of Behaviour Change Theory in Intervention Development

A promising next step towards enhancing the likelihood that developed interventions will be both effective and replicable is to follow a systematic approach to intervention development that is guided by behaviour change theory (Michie et al., 2008). Davis et al. (2015) developed the following definition of theory from a consensus exercise with experts across multiple disciplines:

"a set of concepts and/or statements with specification of how phenomena relate to each other, providing an organizing description of a system that accounts for what is known, and explains and predicts phenomena" (Davis et al., 2015, p.127). Theory allows for key goals for intervention development to be addressed: [1] identification of the problem, [2] assessment of the problem, [3] formation of possible solutions, and [4] evaluation of the selected intervention (French et al., 2012; Michie, Atkins, & West, 2014). Additional advantages to using theory during intervention development include: [1] the provision of a large range of options for constructs and mechanisms that may underlie behaviour change, [2] an explanation of where, when, and how behaviours occur, [3] an explanation behind the success or failure of a delivered intervention, and [4] improvement of one's ability to replicate an intervention, providing more opportunity for advancement within a field (Gainforth, West, & Michie, 2015; Michie et al., 2016, 2014)

The Behaviour Change Wheel (BCW) framework (Figure 1) (Michie et al., 2014; Michie, Stralen, & West, 2011) is a framework that holds promise for the development of effective behaviour change interventions. The BCW synthesizes 19 different behaviour change frameworks (Michie et al., 2014), making it a comprehensive and evidence-based framework that allows for intervention targets to be directly linked to specific mechanisms of behaviour change (Michie et al., 2011). The synthesis of numerous behaviour change frameworks allows the BCW to provide a large range of factors that can influence a behaviour, a feature that can be lost with the use of only one or two behaviour change theories (Michie et al., 2011).



Source: Michie et al. (2014)

Figure 1: Behaviour Change Wheel

The BCW has a three-layered structure, with the wheel's core and each hub representing three key stages to behaviour change intervention development: [1] understanding the behaviour, [2] identification of intervention options, and [3] identification of content and implementation options. Starting at the core of the wheel is a capability, opportunity, motivation – behaviour (COM-B) analysis of the desired behaviour to change. Moving outwards, the inner hub encompasses nine intervention functions, defined as "broad components that make up the strategy that allows for interventions to be able to successfully change a behaviour" (Michie et al., 2014). The outer hub of the wheel is representative of seven policy categories to consider based on their ability to support the delivery of intervention functions (Michie et al., 2014) .

The structure of the BCW requires users to begin intervention development at the core of wheel and work towards the outer hub. To begin, a COM-B analysis is conducted to define the desired behaviour in terms of capability (physical or psychological), opportunity (physical or social), or motivation (automatic or reflective) in order to engage in the behaviour. In addition to the six COM-B components, the Theoretical Domains Framework (TDF) (Cane, O'Connor, & Michie, 2012) is an additional framework that provides a more comprehensive list of options by further breaking down COM-B components into 14 succinct domains: knowledge, skills, emotions, memory and attention and decision processes, behavioural regulation, social or professional role and identity, beliefs about capabilities, optimism, beliefs about consequences, intentions, goals, reinforcement, environmental context and resources, and social influences. The TDF has previously been used to further understand factors that impact intervention implementation (Duncan et al., 2012; Phillips et al., 2015; Weatherson, Gainforth, & Jung, 2017). The TDF has also been used to guide interviews specific to improving physical activity in people living with physical disabilities (Tomasone et al., 2017), and focus groups specific to the development of management programs for people with SCI (Bérubé et al., 2015; Munce et al., 2017).

Identified categories of the TDF or COM-B analysis are then linked back to the BCW in a systematic manner by selecting the appropriate intervention functions from the following nine functions: education, persuasion, incentivization, coercion, training, restriction, environmental restructuring, modelling, and enablement (Michie et al., 2014). Once appropriate intervention functions are selected, they are further linked to seven policy categories: communication/marketing, guidelines, recommend or mandate practice, fiscal, regulation, legislation, environmental/social planning, and service provision (Michie et al., 2014). Selected

intervention functions are then also further linked to relevant behaviour change techniques (BCTs), defined as "observable, replicable and irreducible components of an intervention that are designed to change a behaviour" (Michie et al., 2014). The selection of relevant BCTs is based on the current state of the literature and the opinions of current experts in the field of behaviour change. All components of the BCW are then synthesized and evaluated for feasibility using Michie et al.'s (2014) APEASE criteria. APEASE criteria helps to determine if the recommendations developed from research findings are **a**ffordable, **p**ractical, **e**ffective, **a**cceptable, **s**afe, and **e**quitable to implement.

The BCW has been successfully used to develop interventions across a wide range of contexts. For example, the BCW has guided the development of behaviour change interventions aimed at improving recycling behaviour (Gainforth, Sheals, Atkins, Jackson, & Michie, 2016), improving medication management (Sinnott et al., 2015), and the provision of contraception to adolescents (Rubin, Davis, & McKee, 2013). To the best of our knowledge, the BCW has yet to be used as a guiding framework for understanding ways to support participation for the SCI population in the context of aging. With the goal of developing recommendations for interventions that support people aging with SCI, participation was selected as the target behaviour for this thesis. This thesis is the first application of the BCW to develop intervention recommendations for individuals aging with SCI. To maximize the likelihood that the developed recommendations are applicable, translatable, and useful to the target population (people aging with SCI), this thesis was conducted using an integrated knowledge translation (IKT) approach.

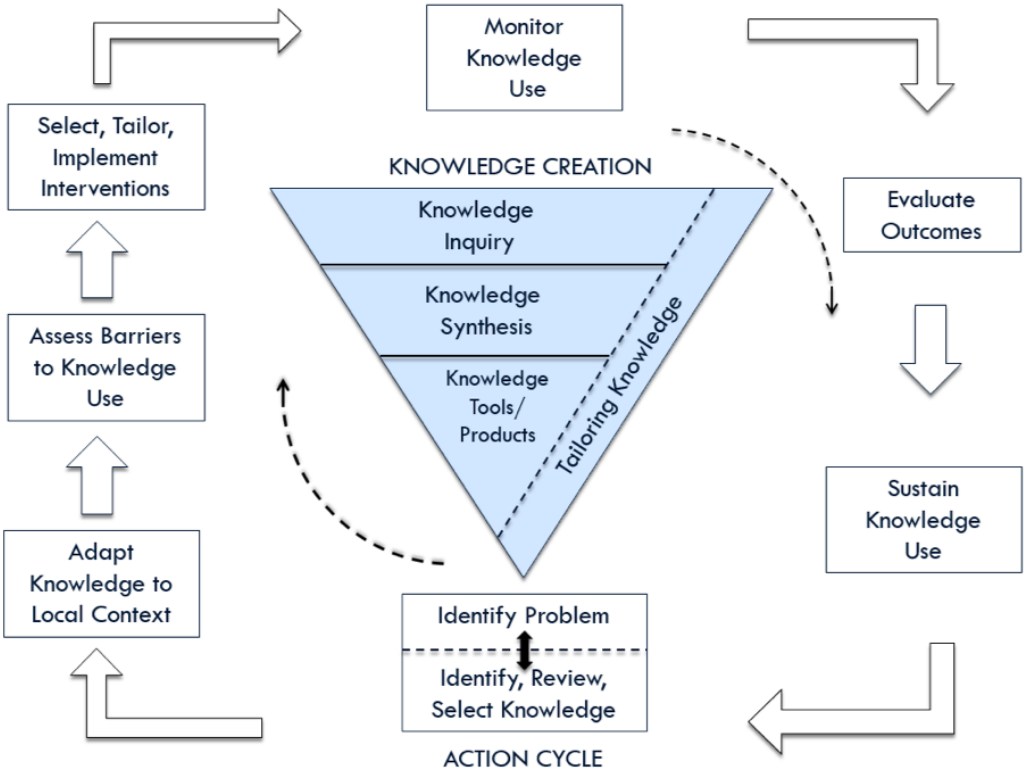
1.8 Integrated Knowledge Translation

Knowledge translation strategies aim to address the slow and unorganized translation of research findings into practice, by maximizing the benefits of research through the development

of evidence-based tools, products, and services (Canadian Institutes of Health Research, 2012; Scott et al., 2012). The Canadian Institutes of Health Research (2006) formally defines knowledge translation as:

> the exchange, synthesis, and ethically-sound application of knowledge – within a complex system of interactions among researchers and users – to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system.

CIHR's knowledge to action (KTA) framework (Figure 2) (Graham et al., 2006) is representative of this definition and breaks the process of knowledge translation into two distinct steps: [1] knowledge creation and [2] action. During the knowledge creation phase, knowledge from primary research studies is obtained, synthesized, and refined in order to create knowledge tools or products. The action cycle outlines seven distinct steps to follow in order to implement developed knowledge tools or products into practice: [1] identification of knowledge gap, [2] adaptation of knowledge to local context, [3] assessment of barriers to knowledge use, [4] selection, tailoring and implementation of intervention, [5] monitoring of knowledge use, [6] evaluation of outcomes, and [7] sustainment of knowledge use. This thesis aligns with the knowledge creation phase of the KTA framework.



Source: Graham et al. (2006)

Figure 2: Knowledge to Action Framework

The benefits of using the KTA framework can be taken even further by adopting an IKT approach. Use of an IKT approach requires intended knowledge users be involved as equal partners in the development, execution, analysis and dissemination of research findings (Graham et al., 2006). Knowledge users are broadly defined as individuals who are likely to be able to use research results to make informed decisions about health (Graham et al., 2006).

Despite the emergence of IKT as a gold-standard approach to knowledge translation, a minimal number of research studies have been conducted in equal partnership with SCI communities throughout the entire research process (Noonan et al., 2014). In a systematic review of knowledge translation interventions in SCI, Noonan et al. (2014) only identified 13 studies, with a majority of these studies being noted as having poor methodological quality. Although more

research initiatives have adopted IKT approaches while working with SCI communities (e.g. Gainforth, Latimer-Cheung, Athanasopoulos, & Martin Ginis, 2015; Gainforth, Latimer-Cheung, Athanasopoulos, Moore, & Martin Ginis, 2014; Martin Ginis et al., 2012), more frequent adoption across the literature may allow for more effective use of research in a timely manner (Kothari & Wathen, 2013; Morris, Wooding, & Grant, 2011; Wathen & MacMillan, 2018).

1.9 Purpose

The overarching aim of this thesis was to develop recommendations for interventions designed to support individuals aging with SCI. Specifically, this thesis aimed to use behaviour change theory and an IKT approach to [1] explore meanings of successful aging with SCI in the context of participation in society, [2] identify barriers and facilitators to participation from the perspectives of people aging with SCI, and [3] develop a further understanding of how to effectively deliver interventions designed to enhance participation while aging with SCI.

2 Methods

2.1 Study Design

To achieve all outlined aims of this thesis, semi-structured interviews were conducted to allow for a more comprehensive understanding of participation that was shaped by individuals with lived experience of aging with a SCI to be developed. Aligning with an IKT approach, meetings were held with community partners throughout the research process.

2.1.1 Integrated Knowledge Translation

In the context of this thesis, three SCI organizations (Spinal Cord Injury Alberta, Spinal Cord Injury British Columbia, and Spinal Cord Injury Ontario) were considered to be the knowledge users and were involved as equal partners with the research team throughout the entirety of the research process. Consultation with one representative from each community organization (TC, SC, CM) resulted in the co-development of the research question, methodology, and dissemination of findings from this thesis. Each representative holds decision making power in terms of which tools, programs, and/or resources are implemented into their respective organizations. Throughout the analysis stage, frequent meetings occurred with each community representative to ensure that both findings and analysis techniques being used continued to address the needs and concerns of each organization. Changes were made to the proposed methodology, approaches to analyses, and presentation/dissemination of findings if required by the organizations. Feasibility of implementing the research findings was assessed in consultation with each representative using Michie et al.'s (2014) APEASE criteria. By involving community partners at each step of the research process, we aimed to ensure the developed knowledge from

the research findings was directly in the hands of our community partners, allowing for the findings to reach SCI community members more easily and in a user-friendly manner.

2.1.2 Researcher Position and Approach

Being a person who does not have a SCI, I recognize that I am not able to develop a first-hand understanding of participation while aging with SCI. Forthcoming interpretation of the results are representative of a more comprehensive understanding of participation, aging, and SCI that is shaped by the perspectives and experiences of individuals with lived experience, and further understood through my philosophical assumptions, the use of behaviour change theory, and my prior experiences with people living with SCI specific to research and volunteer work.

As a researcher, I am cognizant and respective of the fact that end-users will have different perspectives from one another due to differences in social surroundings. Being an IKT researcher, I aim to ensure that the knowledge being created from this research is synthesized into usable formats with the goal of benefitting the end-user (Graham et al., 2006).

I approached this thesis from a pragmatic perspective, a perspective that prioritizes the research question and emphasizes addressing the research question through a course of action (Morgan, 2014). When adopting a pragmatic approach, limited emphasis is placed on seeking a single truth or reality (Dewey, 1931), as the overarching goal of the research is to develop practical recommendations for implementation. Advantages to adopting a pragmatic approach to research include allowance of flexibility of investigative techniques, promotion of collaboration between researchers and community partners with differing philosophical assumptions, and the promotion of prolonged engagement between researchers and end-users (Lincoln & Guba, 1985; Onwuegbuzie & Leech, 2005).

2.2 Participants, Recruitment, and Sample Selection

Recruitment for this study was done in partnership with three Canadian SCI organizations: Spinal Cord Injury Alberta, Spinal Cord Injury British Columbia, and Spinal Cord Injury Ontario. Each organization promoted the study through the forum of their choosing (e.g. e-mailing clients, social media platforms such as Twitter, newsletter advertisements, etc.). Recruitment materials used by the SCI organizations can be found in Appendix A and B. To be eligible for participation, individuals were required to [1] be a minimum of 45 years of age, [2] be a minimum of ten years post-injury, and [3] not have a diagnosed co-morbidity impacting their cognitive function (e.g. Alzheimer's disease, dementia). Forty-five was selected as the minimum age as age-related changes have been evident in the SCI population as early as 45 years of age (Krause & Coker, 2006; McColl et al., 1999). Maximum variation sampling (Sparkes & Smith, 2014) was used to enhance representations of variation across the SCI population in terms of the following parameters: age, gender, level and completeness of injury, mode of mobility, and place of residence (i.e. living in an urban vs. rural community). Selection of parameters was guided by consultation with each of the three SCI community organizations (SC, TC, CM). With respect to sample size, an *a priori* minimum of ten interviews was selected as recommended for TDF interviews (Atkins et al., 2017). Saturation was assessed using Malterud et al.'s (2015) five-point pragmatic criteria for information power: [1] study aim (broad vs. narrow), [2] specificity of sample (dense vs. sparse), [3] use of established theory (present vs. absent), [4] quality of dialogue (high vs. low quality), and [5] analysis strategy (case vs. cross-case). Criteria were assessed both *a priori* (1,3,5) and throughout the study (2,4).

2.2.1 Ethical Consideration

Ethics approval was obtained through the University of British Columbia Okanagan Behavioural Research Ethics Board (see Appendix C). Participants first completed a consent form (see Appendix D) and an online survey to provide basic contact information. EG then contacted each participant by phone to schedule an interview time. Interviews were scheduled at times that were most convenient to each participant. Semi-structured interviews were conducted over the phone or in person, and individually between EG and one participant at a time. Before proceeding with each interview, verbal consent was obtained to both participate in the interview, and to have the interview audio-recorded by EG. Each participant was informed of their right to not answer any questions if they were uncomfortable doing so. To maintain anonymity and confidentiality of participants, direct quotes in this thesis are presented using pseudonyms instead of participants' names.

2.3 Interview Guide

The course of each interview was guided by a semi-structured interview guide (See Appendix E). Content within the interview guide was informed by previous qualitative studies specific to the SCI population (Letts et al., 2011), guidelines for using the TDF to investigate implementation problems (Atkins et al., 2017), and consultation with each of the three SCI community organizations. Each interview began with broad, open-ended questions designed with the purpose of providing an open forum for participants to expand on their personal experiences of participation while aging with SCI. To address the first aim of this study, participants were asked to reflect on their personal experiences while aging with SCI and define what they consider to be "ideal" or "successful" aging in the context of their ability to participate in society. To address the second aim of this study, the next section of questions was designed to allow participants to

indicate any barriers and facilitators to participation that they have experienced or feel they may experience due to aging. Additionally, this allowed for identified barriers and facilitators to be linked to various TDF domains. Probing questions specific to each component of the COM-B model (Atkins et al., 2017; Michie et al., 2014; Sparkes & Smith, 2014) were developed to gain a further understanding of the participants' experiences with each identified barrier and facilitator. To address the third aim of this study, participants were oriented on the study's overarching aim to develop recommendations for interventions specific to enhancing participation for individual aging with SCI. Participants were then asked to think about what content an intervention should contain and their preferred messengers and modes of delivery for programs, tools, and/or resources to support them as they age with SCI. For readability of this thesis, the term "intervention" is used throughout. It is important to note that "intervention" also encapsulates programs, tools, and/or resources. Use of the terms programs, tools, and resources was deemed more appropriate by the SCI organizations to use within the interview guide.

Before recruitment for this thesis began, EG conducted three pilot interviews with one research assistant, one community member with lived experience of aging with SCI, and one researcher with extensive knowledge and experience with qualitative semi-structured interviews and disability research. Changes were made to the interview structure and questions to reflect feedback provided by all interviewees.

2.4 Data Analysis

Audio-recordings of twenty-one interviews were transcribed verbatim using NVivo 11 software by one researcher (EG) and three research assistants (BT, RB, IG). The audio-recording for one interview was inaudible and therefore unable to be transcribed. Each transcript was

reviewed for accuracy by the interviewer (EG). A visual representation of all analyses for this thesis with respect to each stage of intervention development is provided in Figure 3.

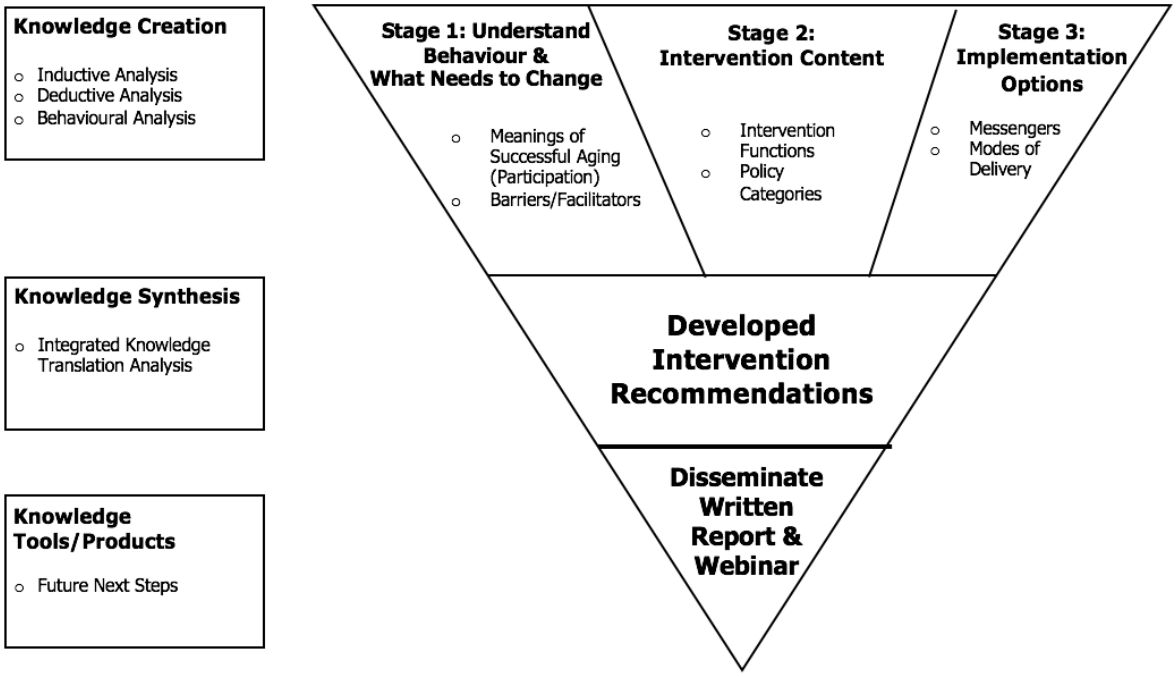


Figure 3: Analyses Mapped to Stages of Behaviour Change Intervention Development

2.4.1 Impact of Researcher Position and Approach on Data Analysis

Traditional views of data analysis suggest that quantitative and qualitative studies generally adopt deductive and inductive approaches to data analysis respectively (Hyde, 2000). Conversely, pragmatism suggests an abductive approach to data analysis, employing a combination of both inductive and deductive approaches (Hyde, 2000; Morgan, 2007). Approaching the data with a mindset that embraces combinations of data collection, analysis, and inference techniques may maximize the potential this study has to effectively support individuals aging with SCI. Abductive reasoning has previously been used to develop practical recommendations (Coppola et al., 2018), maximizing the potential that findings can be translated into practical recommendations to

effectively support individuals aging with SCI. Therefore, aligning with pragmatic principles, an abductive approach to analyses was adopted through the use of both inductive and deductive reasoning to analyze interview transcripts. Detailed methodology for both types of analyses is provided below.

2.4.2 Inductive Analysis

To address Stage 1 of intervention design, an inductive thematic analysis was conducted. Thematic analyses have been deemed useful for summarizing key features across a large data set, highlighting similarities and differences between participants, and generating unexpected insights across the data (Braun & Clarke, 2006; King, 2004; Nowell, Norris, White, & Moules, 2017). The approach used aligned with Braun and Clarke's (2012) phases of thematic analysis. First, one researcher (EG) consistently read and re-read each transcript line-by-line, while making notes of preliminary thoughts and ideas. Once re-familiarized with the data, EG began generating initial codes across all transcripts using NVivo 11 software. Codes were generated with the intent of relevance to the research question: How can we develop recommendations for interventions that will support individuals aging with SCI? Using the identified codes, EG then began to construct potential themes that were representative of the generated codes. Specifically, generated codes were grouped together and reviewed to identify similarities, patterns, and areas of overlap. Field notes taken by EG from the one interview that was unable to be transcribed were compared against the generated themes. During this process, HG, TC, SC, and CM acted as critical friends. EG discussed potential codes and themes in a series of meetings with HG. During these meetings, HG encouraged reflexivity by challenging EG's developed codes and themes and promoting further reflection (Sparkes & Smith, 2014). In an additional meeting, TC, SC, and CM were presented with the newly refined themes. All themes were discussed and modified in this meeting to ensure

that the findings remained relevant and useful to the needs and concerns of each respective organization.

2.4.3 Deductive Analysis

2.4.3.1 Data Extraction

Once all interviews were transcribed, one researcher (EG) identified and extracted barriers, facilitators, and modes of delivery from all interview transcripts. To enhance the likelihood of reliability of extraction, double extraction of barriers, facilitators, and modes of delivery occurred across 33% of interviews *(n=7)* by one research assistant (KW). Discrepancies in extraction were resolved through discussion between EG and KW.

2.4.3.2 Barrier and Facilitator Extraction and Coding

Barrier and facilitator extraction and coding were done to further address Stage 1 of intervention design. Text indicating any factors that promote participation was identified as an "experienced facilitator" or "assumed/hypothetical facilitator." Text indicating any factors that inhibit participation was identified as either an "experienced barrier" or "assumed/hypothetical barrier." The 26 components of participation as noted by the PDAQ (Noreau et al., 2013) were used to determine if the behaviour being described was a participation behaviour. Due to the potential for large amounts of variation in context between each barrier and facilitator, barriers and facilitators identified more than once throughout the interview were kept as separate factors from one another. This allowed for the prevalence of each barrier and facilitator to be examined. Accounting for both experienced and assumed/hypothetical barriers and facilitators allowed for future concerns of those who are early in the aging process with SCI to be addressed, and may

potentially help to address issues of anxiety that have been identified as a long-standing concern towards aging with a SCI (McColl et al., 1999).

Agreed upon barriers and facilitators were transferred into an Excel spreadsheet to be coded as one of the 14 TDF domains. Coding into TDF domains was completed independently by one researcher (EG) and one research assistant (KW). Domains and definitions as per Cane et al.'s (2012) version of the TDF were used as the guiding coding framework (See Appendix F). Any extracted factors that did not align with a TDF domain were coded as "TDF not applicable." Upon completion of each transcript, EG and KW met to discuss their codes and resolve any discrepancies that may have arose while coding. If consensus was not reached for a particular code, a third author with extensive knowledge and experience using the TDF was brought in to resolve the discrepancy (HG).

2.4.3.3 Intervention Function Extraction and Coding

To address Stage 2 of intervention design, intervention functions were extracted and coded. Intervention functions were operationalized as Michie et al.'s (2014) definition: broad components that make up the strategy that allows for interventions to be able to successfully change a behaviour. Agreed upon intervention functions were coded as one of the nine intervention functions within the BCW (Michie et al., 2014). Intervention functions and corresponding definitions as per (Michie et al., 2014) are provided in Appendix G. Once again, if consensus was not reached for a particular intervention function, a third researcher with extensive knowledge and experience with components of behaviour change theory was brought in to resolve the discrepancy (HG).

2.4.3.4 Modes of Delivery Extraction and Coding

To address Stage 3 of intervention design, modes of delivery were extracted and coded. Modes of delivery were operationalized as "ways in which an intervention is delivered and received." Identified modes of delivery were categorized as "who" if the proposed intervention component referred to the intervention messenger (i.e. the person who was delivering the intervention) and "how" if the proposed intervention component referred to how the intervention was received (e.g. online, face-to-face).

Identical methods to barrier, facilitator, and intervention function coding were used to code "how" modes of delivery, with modifications to the guiding coding framework being used. Agreed upon "how" modes of delivery were coded using Carey et al.'s (2016) Mode of Delivery of Behaviour Change Interventions Taxonomy version 0 (MoDTv0) (See Appendix H). Identical methods for achieving consensus from barrier, facilitator, and intervention function were also used for "how" modes of delivery. Extracted "who" components were grouped into broad themes.

2.4.3.4 Reliability

Agreement on barrier and facilitator, intervention function, and mode of delivery extraction was shown using percent agreements. Cohen's Kappa (Cohen, 1968) and prevalence adjusted bias adjusted Kappa (Byrt, Bishop, & Carlin, 1993) was used to show agreement between EG and KW on categorization of barriers and facilitators by TDF domain, categorization of intervention strategies by intervention function, and categorization of "how" modes of delivery by MoDTv0 item (Carey et al., 2016). Inter-coder agreement was determined using strength of agreement values as indicated by Landis and Koch (1977). Landis and Koch (1977) suggest that inter-coder agreement values between 0.41-0.60 indicate "moderate" reliability, values between 0.61 and 0.80

indicate “substantial” reliability, and values between 0.81 and 1.00 indicate “almost perfect” reliability.

2.5 Behaviour Change Wheel Analysis

A behavioural analysis was conducted to further address Stage 2 of intervention design. Deductive analyses allowed for the identification of TDF domains, intervention functions, and modes of delivery that should be considered during intervention development. Identified TDF domains were linked to a matrix of COM-B components mapped against intervention functions (Michie et al., 2014) (See Appendix I), allowing for intervention functions that were most likely to be effective in the context of enhancing participation while aging with SCI to be identified. Identified intervention functions from barrier and facilitator, and intervention function coding were then linked to a matrix of intervention functions mapped against policy categories (Michie et al., 2014) (See Appendix I) allowing for the selection of the most relevant policy categories to supporting the delivery of the identified intervention functions.

2.6 Development of Recommendations

EG and HG worked in partnership with three SCI organizations to shape the methodology of this study, and to ensure that findings remained relevant and were synthesized in a way that was useful for each organization. As such, initial findings from both inductive and deductive analyses were presented in a discussion consisting of EG, HG, SC, TC, and CM. During this discussion, decisions regarding further analyses and dissemination of findings were made. Intervention recommendations were co-developed during the discussion, and evaluated within the context of each of the respective organizations using Michie et al.’s (2014) APEASE criteria.

2.7 Methodological Rigour and Overall Quality of Analysis

Various methods were employed to enhance the methodological rigour of this thesis. Use of abductive reasoning allowed for findings to be developed into practical recommendations, contributing to both the credibility and meaningful coherence of this thesis (Ryba, Haapanen, Mosek, & Ng, 2012; Tracy, 2010). Adoption of an IKT approach to the thesis contributes to the worthiness of the topic, as the research question came directly from SCI community members and SCI organizations. Throughout analysis, the roles of HG, SC, TC, and CM as critical friends allowed for questioning of the development of themes and recommendations, as well as the encouragement of alternative interpretation and further reflection (Sparkes & Smith, 2014), Aligning with prioritization of the SCI community, ethical considerations for participants were strongly considered before, throughout, and after the research process. Extra measures were also taken to ensure comfort and confidentiality of all participants before, throughout, and after the research process.

3 Results

3.1 Participants

In total, EG conducted 22 interviews with individuals living with SCI *(Mean Age: 55.64 years, SD: 7.84; Range: 45-76 years; Mean Years Post-Injury: 32.27 years, SD: 9.43, Range: 15-58 years)* between December 2017 and March 2018. Saturation was reached at 22 interviews, as new themes no longer emerged at 19 interviews. Twenty-one interviews took place over the phone and one interview took place in person as per preference by the participant. Interviews lasted between 38 and 116 minutes *(Mean:* 73.91 minutes, *SD:* 19.54*)*. Of the 22 participants, 12 *(55%)* identified as male and 10 *(45%)* identified as female. Sixty-four percent (*n=14)* indicated their type of injury as paraplegia, and 36% *(n=8)* indicated their type of injury as tetraplegia. A wide variety of modes of mobility were used by participants. Modes of mobility included the use of a manual chair *(n=17)*, power chair *(n=3)*, use of a walker *(n=1)*, and walking independently *(n=1)*. Ten percent of participants *(n=2)* indicated the use of multiple modes of mobility. 77% of participants *(n=17)* indicated residence in an urban area, operationalized as a city or town with a population greater than 50,000 people, and 23% of participants *(n=5)* indicated residence in a rural area, operationalized as a city or town with less than 50,000 people. Across the SCI organizations, 18% were affiliated with Spinal Cord Injury Ontario *(n=4)*, 9% were affiliated with Spinal Cord Injury Alberta *(n=2)*, and 73% were affiliated with Spinal Cord Injury British Columbia *(n=16)*.

3.2 Results: Inductive Analysis

With regards to Stage 1 of intervention design, three themes were developed to further understand how we can create recommendations to support individuals aging with SCI, and will be presented as follows: [1] successfully aging with SCI is an interconnected and multi-faceted

concept, [2] interpersonal, intrapersonal, and environmental barriers prevent full participation while aging with SCI, and [3] the outlook and actions of yourself and those around you are key factors to full participation while aging with a SCI. Direct quotes from participants are presented within each theme.

3.2.1 Successfully Aging with SCI is an Interconnected and Multi-Faceted Concept

Similar to previously established successful aging models (Freedman, Agree, Martin, & Cornman, 2006; Rowe & Kahn, 1997), definitions of successful aging with SCI involved a series of factors that were all of equal importance to aging well while having the ability to influence one another. Unlike most commonly used successful aging models which focus on the prevention of more negatively viewed factors (e.g. disease), emphasis was placed on the improvement and/or maintenance of more positively viewed factors. Specifically, the following three factors were identified as important and influential to successful aging: health and well-being, independence, and social participation. Each of the identified factors are described in further detail below.

3.2.1.1 Improvement/Maintenance of Health and Well-Being

All participants strongly identified with the importance of maintaining and/or improving their health and well-being as they age. Despite the consistency of the importance of overall health and well-being, definitions of what constituted as overall health and well-being differed across participants. Many participants viewed health from a more holistic perspective, where different components of health (physical, mental, and social) are all important in achieving an overall picture of health and well-being. A majority of participants specifically spoke to the importance of physical and mental health, and the large influence both have on one another. Presented below are

one participant's perceptions of the importance of mental and physical health, and the role that mental health has on a person's physical health:

> *If you have emotional problems, I think that's when your body can start to break down and I, I've just seen it. I've seen people with emotional problems and they just seem to be, all of a sudden, they have a lot of physical problems too and I don't know if that's just the way it works or if that's partly… I don't know your mind is a pretty amazing organ and I think it controls a lot.* (Connor)

Some participants incorporated three components of health and spoke to the importance of the connection that exists between physical, mental, and social health, and how change in one will largely influence the remaining. Presented below is a participant's ideal picture of aging in a healthy manner and how changes across all three components would impact their overall health and well-being:

> *My ideal would be incorporating mind, body, and social because they are all interconnected and my idea of aging healthy would be to keep active… as active as I possibly can but that it's socially and physically which will affect me emotionally. So… when you become physically ill, become socially isolated, it also causes quite often, depression, anxiety, they are all inter-related.* (Katie)

Conversely, some participants did not speak to holistic health and placed emphasis solely on physical components of health. An example of this mindset is presented in the quote below:

> *I think the big challenge I'm looking at in the aging side of things isn't the mental side of things, it's the physical side.* (Mark)

3.2.1.2 Maintenance of Independence

As defined by the United Nations Convention on the Rights of Persons with Disabilities (2006), independence encompasses three key criteria: [1] individual autonomy, [2] opportunity to be involved in decision-making processes, and [3] opportunity to access the physical, social, economic, and cultural environment. Across all interviews, participants placed a high level of importance on being able to maintain their independence as they age. When asked what it meant to successfully age, 95% *(n=20)* of participants spoke highly to the importance of remaining independent and attributed independence as being a highly motivating factor for engaging in activities that promote overall health and well-being. An example of the overpowering importance of independence and its heavy influence on one's autonomy is indicated in the quote below:

> *Independence is the main [important life aspect]. Umm…that's huge, being able to do what I want to do, like you know having the freedom to not… to stay where I am and have the choice. I guess doing what I want to do and not be locked into… If I lost my independence, I'd be locked into somebody else's schedule or whatever, and I see that with some people and it's totally not what I want.* (Frederique)

It is important to note that the need to "improve" independence was not indicated by participants. However, more focus was placed on the need to "maintain" independence as much as possible with increasing age. The participant speaking below outlines how her independence goals have changed as she's been aging:

> *Just being able to maintain my independence as far as not having to depend on [others]… I don't really want to move to a facility where somebody has to care for me. Umm… but I see that as kind of unavoidable.* (Jessica)

Diverse responses emerged when discussing feelings about needing to receive help from others. On one end, some participants felt they were not comfortable having to ask others for help. Instead, these participants felt it was important to prove they could do as much on their own for as long as they possibly can. An example quote from one participant is presented below:

> *I don't like asking for help, nobody does. Especially, if you… you know people with SCI right, like you want to keep your independence… you want to keep… you prove you're independent, you do it all by yourself.* (Frederique)

Conversely, other participants felt it was important to be comfortable asking for and accepting help from others in order to remain independent, and be able to have a choice in which activities they can partake in, as there may be certain activities where help from others is required to make an activity possible. The participant below is discussing the importance of accepting help when you are presented with the opportunity to receive help:

> *You just got to know [what] different people's breaking points are and human nature, and then try to take advantage of as many people as you can cause, well not take advantage… but if you have the opportunity to have somebody do something, we always do [as much as we can, then ask for further help], cause I mean it takes away from what our friends have to. If someone drops by here, they're going to be prepared to be changing lightbulbs and reaching things we can't reach, but we don't want to throw everything on [our friends]. I guess a part of it is not being afraid to ask people for help.* (Jeremy)

3.2.1.3 Improvement/Maintenance of Social Participation

Improving upon or maintaining the nature and extent of social participation was described as an important factor to successfully aging with SCI. Examples of prioritized and commonly noted

experiences of social participation included spending time with family, spending time with friends (includes peers living with SCI), engaging in physical activity (includes sport and exercise), and engaging is leisurely activities (e.g. cooking, travelling, gardening). Benefits of improved or maintained social participation were attributed primarily to the quality of participants' experiences. When speaking to the quality of their experiences, continued social participation with increasing age lead to a number of positive feelings including having a purpose or meaning, making a contribution or difference in the community, feeling a sense of belonging to the community, satisfaction with mentoring others, development or maintenance of an identity, and continuing to be challenged. The participant quoted below is speaking to the meaning of being able to spend time with his family:

> *I put a significant focus on family and being together and I've always spent a lot of time with my kids and of course my wife and that's the core. That's the core reason why I can do anything really is to have that community around me.* (Robin)

In contrast to a majority of participants, 14% of participants *(n=3)* spoke to the importance of needing time alone and not always wanting to be around other people. The participant quoted below felt that she appreciated time she spent alone much more as she has gotten older. *"I'm not [just] okay with [spending time by myself], I need it… I feel like I need it."* (Jessica)

Some participants also spoke to the importance of the amount of participation experiences they partake in. Below is a participant's response when asked why it was important to continue being involved in more activities throughout their community:

> *Well yeah sure, to a certain extent yeah… I see the benefit of [staying involved in the community] because you know I just… the more things you do, the more active you are, the more chance you have the opportunity to… be around people.* (Jakob)

Unlike other participation behaviours, exercise and strenuous physical activity were viewed by 20% of participants *(n=4)* as somewhat detrimental if overdone, despite the importance of exercise noted by the majority of participants. These participants felt that over-exercising contributed to the rapid progression of wear and tear on their shoulder joints. The participant below speaks to the importance of being aware of not "overdoing it" with exercise:

> *[It's important to] also keep up some exercise but not overdo. I'd say when I went to rehab back in the 60s, the emphasis was [to] do everything you can and a little bit more, never give up you just go and go and go. Well, you can overdo it. It was never mentioned that you could wear out your shoulders, your joints are going to go. This is something which should be I feel… really put a big emphasis on.* (Brian)

3.2.2 Intrapersonal, Interpersonal, and Environmental Barriers Prevent Participation

A variety of interpersonal, intrapersonal, and environmental issues arose when participants spoke to the challenges or concerns they have about aging with SCI. Each of the sub-themes presented below are inclusive of both issues that participants have already experienced, as well as challenges that participants fear they will experience in the future. The sub-themes below include: feeling there is lack of aging and SCI specific resources and knowledge, experiences of aging-related complications, experiences of intrapersonal emotional distress, and frustrations with community priorities.

3.2.2.1 Lack of Aging and SCI Specific Resources/Knowledge

Participants felt differently from one another when discussing the availability and quality of resources designed to support aging with SCI. Examples of resources referenced in interviews included research findings, online resources (e.g. information websites, forums, videos), and

knowledgeable health care specialists. However, all participants felt that learning from their own personal experiences was a valuable resource. The participant below is speaking to the value of learning from his own personal experiences to be able to discover what works best for him:

> *Yeah, I think it truly comes from learning your own personal limitations. I think you really have to go through the personal frustration and personal discovery to really have the right system. Nobody could have really told me early on, 'Well, you should do this… and this, and this.' You know it all has to come from that discovery and the support for that discovery.* (Robin)

Some participants felt that the only resource available to them was their own personal experience. When asked if only learning from personal experience was enough to age well, differences were found across responses. Participants attributed a lack of resources to various reasons including an increased need for SCI-specific aging research, a lack of awareness of how or where to access any pre-existing resources, and the appearance of a lack of interest in aging-related issues shown by SCI organizations. For example, the participant below is speaking to how she would like to see more research done looking at menopause in women aging with SCI:

> *And I mean as a woman, one of my biggest concerns is menopause and how that's going to affect me. I'd like there to be more people that are aging with a spinal cord injury, especially women who kind of push for research. The kind of things that are going on with our body. I have lots of friends you know who have issues right now and that are around my age. So yeah, I'd like to see more women, research studies pushing for that.* (Nicole)

Interestingly, participants who identified as either employees of a SCI organization or members of a community-wide peer group felt they were not as disadvantaged in terms of access to knowledge and resources. Two SCI organization staff felt they had better access to current research and

information compared to others, however information and resources specific to aging with SCI were still limited. Community-wide peer group members felt a majority of their resources came from online social media forums where group members would share their resources, or hearing the personal experiences of other group members. The participant quoted below identified as a part-time worker for a SCI community organization:

> *I think I'm better equipped [with resources and information] than the average person. Mostly because of my job and the access to the information that I have. Like right now I get a steady diet of information that is SCI-related because that's my job. So… it's through connected networks, through my co-workers.* (Sadie)

Experiences with care providers (e.g. family physicians, social workers, long-term care providers, etc.) differed across participants, suggesting inconsistency in the quality of care received by people aging with SCI. Some of the participants who spoke about experiences with care providers while aging shared very positive experiences. The participant quoted below is speaking to the positive experience he has had with his current care providers once moving to a larger city:

> *I got connected to a physiatrist, and I didn't even know what a physiatrist was [during rehab]. The stuff [my physiatrist] and [my occupational therapist in my current city] [have done] … between those two, and even my urologist... they increased my health twice as good … you know take a gram of Vitamin C for your bladder, um connecting me up with [respective SCI organization] so I could you know meet people and be active. Increased my lifestyle greatly, my general health, and everything.* (Kenneth)

Contrarily, some participants also spoke about their experiences and felt there was a lack of knowledge among care providers (e.g. physicians, social workers, long-term care workers) of people living with SCI. Lack of knowledge was frequently attributed to either lack of experience

or lack of interest in working with the SCI population. For example, the participant quoted below credits the positive experiences he has had during doctors' appointments to his doctor having more experience working with people living with SCI:

> *Probably a lot of doctors don't deal with SCI people right. So, you know… I'm lucky my doctor has four [SCI] patients. Some doctors, [people living with SCI] are [their] only patient or they don't have any patients and then somebody new comes along and they're not very knowledgeable about it.* (Brendan)

3.2.2.2 Aging-Related Complications

In addition to the importance of maintaining physical health, all participants spoke about concerns they had with age-related physiological changes after living with a long-term SCI. Concerns varied across participants, however some of the most commonly noted changes included: overuse injuries (primarily to the shoulders joints), weight gain, pain (nociceptive/general bodily pain or neuropathic), and difficulties with bladder and bowel function. All seventeen participants who indicated use of a manual wheelchair, as well as one participant who transitioned from a manual to a power wheelchair noted concerns with overuse injuries to their shoulders. The two participants who do not use a wheelchair as their primary mode of mobility did not indicate any issues with overuse injuries to their shoulders. The participant below indicated use of a manual chair and is speaking to her experience with overuse injuries in her shoulders while aging:

> *Yeah… I didn't have to focus on [my health] ever right, because I was in good health. I was active. Um… you know and things crop up, like overuse, and just with aging, overuse syndrome. I've got a whole bunch of tears in my shoulders… […] You know as I get older, it's just like 'Oh they say it's wear and tear, that sort of thing and it just happens.' So, um… it's something that I didn't have to deal with because I wasn't older. Now it's because*

of 40 some years of wheeling, transferring and lifting my body weight and it's taken a toll on my muscles and joints and that sort of thing. (Frederique)

It is important to note that despite the commonality of the concerns noted above, not all participants experienced issues with the latter three concerns (weight gain, pain, and difficulties with bladder and bowel function). Experiences of these concerns varied across participants due to a number of factors such as the presence of additional secondary complications, and lifestyle factors (e.g. level of exercise, type of diet).

3.2.2.3 Intrapersonal Emotional Distress

In a similar manner to physical health, participants expressed that aging-related changes fostered feelings of anxiety and worry. One of the most commonly noted fears indicated by participants was the fear of being completely dependent on others, reinforcing the importance of maintaining independence. Quoted below is a participant who felt vulnerable due to the potential of full loss of independence:

Well… aging is a process we are all going to go through, it would be nice if one could go through aging without any other ailments. It seems as we get older, there's all these other side effects which we run into. Uh, trying to think… in plain words, I don't look forward to aging at all, it's scary. At one point, for all I know I will be completely dependent on other people, even to sit me up and maybe feed me. That's a very scary thought, so no it's something one doesn't even want to think about too much… at least I don't. (Brian)

Participants also expressed concern towards feelings of being a burden and not being able to properly support their family and friends. For example, the participant quoted below is explaining what makes him feel like he may become a burden as he continues to get older:

It's easy to feel like as you're aging that because you know things are going to get harder, that you might feel like a burden to other people in your life and you don't want to become a burden; there's some emotional stuff attached to that. (Christopher)

Interestingly, the family members and friends that participants expressed concerns on being able to care for differed across participants, depending on their age and family situations. For example, participants who struggled with the idea of not being able to properly care for their aging parents were more likely to be below the age of 55, whereas participants over the age of 60 seemed to express more concern about being able to play with grandchildren or caring for their aging spouse. The participant quoted below is sharing her frustration with being unable to properly care for her parents as they age:

And like aging isn't something I really think about a lot... although as my parents age, I'm uh kind of pissed off at myself that I'm in a wheelchair and I can't help them more but again that's life, right? (Alannah)

Identified triggers of anxiety and worry were not always specific to future events. Some participants shared how being injured at a younger age made it more difficult to have time to emotionally deal with their injury due to the demands of other life responsibilities (e.g. going back to school, being a parent, being an athlete, etc.). The participant below is speaking to an emotional struggle she experienced when her work began to slow down and her children became older:

Gosh, I think for me like, right now even you know… reflecting on the last 20 years and almost you know… I was going to say just starting to maybe deal with parts of the injury that maybe I never dealt with before because you know when I had my injury, I was young, my kids were young and so you just get on with it right? And just move forward without maybe addressing some of the emotional effects that it has on you because maybe you

didn't really realize them at the time. So, I think now you know when life slows down, I'm having the opportunity to sort of reflect back and think, "How do I feel about having a spinal cord injury?" Because the last 20 years have been so successful and gone by so fast (Sarah)

3.2.2.4 Frustration with Community Priorities

People living with SCI deal with accessibility issues throughout their community, regardless of age. Across interviews, participants spoke about experiencing feelings of frustration and decreased levels of tolerance when dealing with accessibility issues at an older age. Many participants felt it was simpler to deal with accessibility issues at a younger age, as aging-related physiological changes (e.g. overuse injuries, weight gain) had not yet occurred, making tasks such as wheeling over a curb simpler to do. For example, the participant quoted below speaks to her frustration when going to visit her doctor's office:

I'm also getting to the point where now and then if this is happening I find it different like say it's a doctor… well then, I want a different doctor's office, like my doctor's office is brutal. He moved, he moved to a building that is just brutal and so now I'm getting to the point as I'm aging [where] I want good access so there's no struggling like moving from my comfortable environment. I don't want to leave knowing that I got to park three blocks away getting to my doctor's office… completely inaccessible, hoping somebody's standing outside the door… like these are just things as I'm aging I'm getting less tolerant of. (Brenda)

Additionally, feelings of frustration from participants extended to the allocation of government resources. As the baby boomer generation continues to rapidly age, governments across several developed countries worldwide have been placing more financial priority on

supports (e.g. health care, modes of mobility) specific to the general elderly population (Anderson & Hussey, 2000). As such, some participants felt there is a lack of attention placed on the needs of people living with SCI during their lifetime, resulting in feelings of frustration and neglect with older age. For example, the participant quoted below is explaining why he feels that adaptive technology has not evolved to its full potential:

> *I just feel they could've done [develop more adaptive technology], but it's just that there wasn't enough [money]... there was more money in [other issues]. I know it's cynical but there's more money in people being sick than there is in helping them you know. But uh… that's it you know, it's all just profits. Someone has to invent something and then get it to market. There has to be money and maybe there isn't enough money in something like that I don't know. But you would think that they could have some technology that would've been able to get me up a flight of stairs... I mean you get someone to the moon. You know if there was a military reason for me to get to the top of the stairs, I'm sure I'd have [something that would allow me to get to the top of the stairs] you know… So anyways it's just… it was frustrating.* (Jeremy)

Another example of frustration with allocation of resources is presented below, where the participant explains how difficult it is to find a parking spot as seniors who are not living with a physical disability are being provided with accessible parking permits:

> *You know, there, you know, the recent Christmas season it was horrendous and frustrating just to find a [parking] spot. You know especially with this snow and well it's crazy. You know, you have say hundreds and thousands of seniors taking up those spots. They can still walk to the next parking spot just 10 feet away or 5 feet sometimes. But you know, I got a van and need the extra wide spots, most times I'm hooped.* (Dean)

3.2.3 Outlook and Actions of Yourself and Others Impact Full Participation

Within this theme, three key sub-themes emerged as important factors for individuals to be able to enhance their experiences of full participation: self-advocacy and being proactive, being aware and prepared, and having strong support systems. These sub-themes are representative of different intrapersonal and interpersonal factors that may enhance/lead to full participation while aging with a SCI, as well as potentially addressing the challenges noted above.

3.2.3.1 Self-Advocacy and Being Proactive

In the context of participation, self-advocacy has been broadly defined as being aware of one's own rights, therefore acting on one's own behalf to ensure the human right to full participation is not violated (Test, Fowler, Brewer, & Wood, 2005). Participants who indicated the importance of self-advocacy felt that beginning to or continuing to take responsibility of their own care was imperative to aging well. The emphasized importance of taking responsibility for one's own care may be due to the complexity and individuality of the aging experience, and how individuals will age in different ways from one another. Presented below is a participant speaking to their beliefs on the importance of being a self-advocate:

> *You have to be your own best advocate. If you are the one that's just going to sit around until somebody does [something] for you, you're not going to do anything.* (Mark)

Ways in which responsibility for care was taken included promptly asking questions about health issues to care-providers, independently self-educating and researching for information, and becoming involved in research opportunities and studies. For example, the participant quoted below is speaking to how he acts as his own advocate when different issues arise:

> *Haaa… where do I go look for information? I suppose I tend to tackle every problem on a case by case and then I start to be my own… like I said my own best advocate and I'll*

look into okay what, what's going on, what are other people… what have they done and then see what the options are, plan and, uh, you know… attack the problem and see what people made it better. (Mark)

Participants also spoke to the importance of advocating for appropriate and timely health care and accessible communities. In fact, three participants had already begun communicating with their respective municipal governments to work towards implementing changes to promote more accessible communities and gym facilities. The participant below is sharing details about an exercise group her and a group of friends started up:

I'm working with a group of two people, um we live in [name of city] and we call ourselves [Name of Exercise Group], but we are trying to create more opportunities for people who don't want to go to the [main exercise facility] all of the time… so we're trying to work on creating activities here to keep as active, healthy and socially connected. We even had a meeting with the mayor and a city councilor about a month ago, and I think that's helped me find purpose too. (Katie)

3.2.3.2 Being Aware and Prepared

A majority of participants felt that it was important to be aware of the aging process and its corresponding physical, mental, and social impacts. Equally as important was to act accordingly based on these impacts. Examples of ways to act accordingly included pre-planning daily schedules, making modifications to everyday equipment (e.g. vehicles, wheelchairs), and making modifications to the type of activities to engage in.

Conversely, some participants also felt that awareness to the aging process was stressful and preferred to continue everyday life without thinking too much. The participant quoted below

is questioning if it is best for her psychologically to know as much information about aging as she does:

> *[Aging's] pretty scary, feeling vulnerable. Maybe it was easier… I ask myself sometimes, was it easier before… psychologically when I didn't know these things. Sometimes ignorance is a bliss.* (Katie)

All participants indicated that everyday activities (e.g. self-care, running errands) take longer with increasing age. Fittingly, one of the most commonly noted changes mentioned by participants was the importance of strategically planning daily schedules ahead of time, allowing for a decreased amount of transferring. For example, the participant below is explaining how she completes all of her errands within the same trip so she does not have to constantly be transferring from her vehicle to her wheelchair:

> *I mean if I have to go make multiple stops, like you know… I would say that with my aging now I plan so much more, right? Um, so you know I don't have to transfer as much. I don't have to be in and out of my car you know even just wheeling actually is a little bit better.* (Nicole)

In contrast to a majority of participants, participants who identified living in a long-term care facility *(n=2)* felt they were immune to changing their daily routines as they have adapted to living with their SCI for such a long period of time. Interestingly, both participants were two of the oldest participants interviewed. An example quote from one of the participants is provided below:

> *Well, I think the main part is, the older ones we've already adapted to life in a wheelchair or whatever... we have to adapt and it's hard to make another change.* (Brian)

As mentioned previously, many participants spoke to the importance of planning ahead to make modifications to their everyday equipment. Making modifications was associated with being able to continue participating in society and being as independent as possible. Some of the most commonly noted changes included transitions between manual to power chairs, cars to vans, and the addition of assists throughout the home. For example, the participant below is speaking to the importance of being able to use assistive technology as early as possible:

> *You have what is… overhead lifts to transfer into a chair or into a bed. Those are things which maybe a person has to start using earlier in life and not just when the time comes and one has no choice. It's just to start using the aids which are out there, before you're forced into using them.* (Brian)

Some participants also spoke to their decisions to avoid certain activities they participate in as they get older. Reasons for avoidance of activities included increased fears of further injury and increased fatigue with older age. For example, the participant below is speaking to how he is now much more cautious when deciding which activities to do:

> *There's a certain amount of fear of doing activities that will say throw a shoulder out or break a leg or… I mean I'm way more cautious about that. Certainly, just knowing that my body is aging and seeing the fact that I don't feel as quick both at the skin level and at the muscle level, I certainly don't feel as quick as I did twenty, thirty years ago. So yeah, what I have to learn is to change the way I do things so that I won't injure myself because that would really… you know I couldn't do what I do right now [and] that would certainly make me age a lot quicker.* (Robin)

As opposed to the avoidance of activities, participants also spoke to the value of changing the types of activities they decide to engage in. Participants who identified as athletes or spent a

large amount of time playing sports spoke to transitioning into different roles within a team (e.g. coach, bookkeeper) or transitioning from sport to leisurely exercise. For example, the participant below is speaking to how she no longer plays sport competitively, and more so for recreation purposes:

> *So now, whatever activity I'm going to do, and I like to do lots - you know I like to participate in any activities that I can (Yup) but only on, um not at a competitive level... only for relaxation or enjoyment, or that um just... sense of belonging so that um you know I'm not... so that I know that I can still participate in community, participate in life, and still have activities that I can share with my friends, with my family.* (Sarah)

3.2.3.3 Having Strong Support Systems

Participants indicated that being able to provide and receive support from people in their lives has played a large role in improving and/or maintaining full participation while aging with SCI. The strongest support systems identified by participants included spouses and partners, family, friends, teammates, and peers (other people who are also living with SCI).

Practical support was primarily *received* from family members and friends who do not have a SCI and were living in close proximity of the participant, as physical limitations posed challenges for certain everyday tasks and activities. For a majority of participants, practical support was provided for tasks that may be difficult for someone living with SCI to do both within the home (e.g. completing a household chore) and out in the community (e.g. wheeling up a steep hill). Participants who identified as having a high-level cervical injury *(n=2)* spoke to the importance of receiving everyday practical support from care-aid workers, in addition to practical support received from friends and family. Conversely, participants who did not primarily use a wheelchair-based mode of mobility did not speak to the value of receiving practical support, and spoke more

to the value they feel being able to provide practical support to others. For example, the participant below is speaking to the emotional value he feels when providing practical support to his peers:

> *Yeah working with [name of peer]and [name of SCI community group] and helping him out whenever he needs something hauled around or anything. The thanks I get is just… it's just worth everything.* (Logan)

Participants also felt that it was important for those who are helping them with everyday tasks and activities to recognize how important their independence is, yet to still be there to help as needed. The participant quoted below is acknowledging how important it is to her that her family and friends provide practical support, while still recognizing the importance of her independence:

> *[Knowing I have support when I need it] was so you know, enlightening and confirming for me. And now that I am on my own… like knowing when I fell the other night, I could have called my girlfriend and she would have been here in a heartbeat. You know just knowing that and being more comfortable with that. But yeah, you know I have some pretty great people in my life, so they know kind of when to ask and not to be intrusive or overstepping I guess. Or they don't go into like go mode, like someone's not knocking on my door every day to make sure I'm okay… that would drive me nuts.* (Brenda)

It was important for participants to both provide and receive emotional support amongst all their support systems. Yet, differences in the type of emotional support received were dependent on who was providing support. For example, the participant below is speaking to how her family helps her feel that emotionally, she does not have a disability:

> *They probably don't really um… they don't see the disability. My- I mean the people around me don't see my disability. Um, this is a tough one because I mean I'm reflecting on my family, right? I mean they know what I can and can't [do], but then they also don't*

emotionally even treat me like I have a disability. So... I don't always feel like I have a disability, emotionally. (Sarah)

Interestingly, a majority of participants did not have specific examples of emotional support from their family members and friends who were not living with a SCI. Instead, participants spoke to the importance of being there for one another, and being able to share experiences with one another.

The type of support provided by peers was unique to all other support systems identified above. Presented below is a quote from a participant who is explaining what makes peer support different from the support she receives from her family:

Yeah exactly, you don't even have to explain it. [Peers] get it. It's not always the most comfortable thing I guess to talk about life, your UTIs or whatever, you can talk about it with your parents and even with my sister. I don't really talk about it that much, they just don't get it. But peers get it right? (Alannah)

Peers were frequently other individuals living with SCI that they had met and developed friendships with *after* acquiring a SCI. Conversations with peers frequently revolved around sharing each other's personal experiences and tips for dealing with various issues (e.g., health complications, accessible travel). Although practical support was not common with peers, many participants felt that being able to *directly* relate with their peers was one of the most valuable forms of emotional support to them. The participant quoted below is explaining the value of peer support:

Peer to peer connections are so important because we learn so much from each other. I think that's probably one of the most valuable resources because things become real when

you know the person that's doing [this activity/task], or has seen [that activity/task]. (Sadie)

However, some participants also emphasized that they were also able to relate to their friends and family who do not have a SCI, however were also aging. An example quote is provided below:

"I don't think [the things that happen with aging are] different than the general population because I did talk to my able-bodied friends and I talked to my injured friends and you know we're just aging in general so you know. Are you more tired a little bit? Are you more tired because you're aging? Are you more tired because of a spinal cord injury? Um, so… it's kind of hard to tell, like when I talk to say the general population I feel we're all kind of dealing with the same things. (Brenda)

3.3 Results: Deductive Analysis

3.3.1 Barrier and Facilitator Extraction

A total of 112 factors (30 experienced barriers, 55 experienced facilitators, 6 hypothetical/assumed barriers, 21 hypothetical/assumed facilitators) were extracted by two independent coders (EG, KW) across 33% of transcripts *(n=7)*. Percent agreement across the seven transcripts was 64.9%. Across the remaining 14 transcripts, an additional 118 factors were extracted by EG, resulting in a total of 230 factors (74 experienced barriers, 100 experienced facilitators, 22 hypothetical/assumed barriers, 34 hypothetical/assumed facilitators).

3.3.2 Barrier and Facilitator Coding

During TDF coding, 19 factors (13 barriers, 2 facilitators, 3 hypothetical/assumed barriers, 1 hypothetical/assumed facilitator) were excluded as they were not aging-specific or did not directly affect participation behaviours, leaving a total of 211 factors. Inter-coder agreement of the

TDF domains fell between "substantial" and "almost perfect" *(Kappa=0.69±0.18; PABAK=0.91±0.06)*. Twenty-five factors were coded to two TDF domains, resulting in a total of 236 codes. Four disagreements arose during coding between EG and KW that required consultation with HG.

Table 1 presents the number and percent total of factors identified across TDF domains. *Environmental context and resources (ECR) (n=135, 57.20% of TDF codes across all four categories)* was the most commonly coded TDF domain across all four categories. *Optimism, Reinforcement and Decision Making* were the only three TDF domains not coded across any of the four categories. Factors related to *Beliefs about Capabilities* and *Skills* were discussed more as barriers than facilitators. More facilitators than barriers were discussed in relation to *Social Influences*. *Beliefs about Consequences* is the only TDF domain that was discussed a similar amount across all four categories. Across experienced barriers*, ECR (n=35, 49.30%), Skills (n=16, 22.54%), Beliefs about Capabilities (n=10, 14.08%)* and *Beliefs about Consequences (n=5,7.04%)* were the most commonly coded TDF domains, accounting for 91.55% of the total. Of the 16 *Skills* codes, 88% *(n=14)* were specific to a physical bodily change that prevented participation, and only 13% *(n=2)* were specific to the inability to participate due to lack of an acquired skill. Within hypothetical/assumed barriers, over 50% of codes were specific to *ECR (n=7, 30.43%)* and *Emotion (n=5, 21.74%). ECR* represented 60.19% *(n=65)* of the TDF codes within the facilitator category. Although *Social Influences* were not coded for across either barrier-based category, the domain was coded in 21.30% *(n=23)* of codes in the facilitator category. All *TDF not applicable* codes were within the facilitator category. Interestingly, each *TDF not applicable* code was further coded as the *Nature of the Behaviour* domain, a domain previously included in the initial version of the TDF (Michie et al., 2005). Constructs specific to *Nature of the Behaviour* include direct

experience/past behaviour and representation of the task (Michie et al., 2005). Within this domain, continuing to be engaged in everyday activities (i.e. self-care, exercising) enhanced both the quantity and quality of participation experiences. Discussions of hypothetical/assumed facilitators were primarily related to *ECR (n=28,82.35%)*. Quotes representative of each identified TDF domain are provided in Table 10 (Appendix J).

Table 1 *Number and Percent Total of TDF Domain by Category*

TDF Domain	*Barriers (n)*	*Hyp/As Barriers (n)*	*Facilitator (n)*	*Hyp/As Facilitator (n)*	*Total (n)*	*Total (%)*
Behavioural Regulation	0	1	2	0	3	1.27
Beliefs about Capabilities	10	3	0	1	14	5.93
Beliefs about Consequences	5	3	5	3	16	6.78
Decision Making	0	0	0	0	0	0
Emotion	1	5	0	0	6	2.54
Environmental Context and Resources	35	7	65	28	135	57.20
Goals	0	0	0	1	1	0.43
Intentions	0	0	1	0	1	0.43
Knowledge	0	1	2	0	3	1.27
Memory, attention and decision processes	0	1	0	0	1	0.43
Optimism	0	0	0	0	0	0
Reinforcement	0	0	0	0	0	0
Skills (Total)	16	1	1	1	19	8.05
Body Change	14	1	1	0	16	6.78
Ability	2	0	0	1	3	1.27
Social Influences	3	1	23	0	27	11.44
Social/Professional Role and Identity	1	0	3	0	4	1.69
TDF Not Applicable	0	0	6	0	6	2.54
Total (n)	71	23	108	34	236	

Note: The total (n and %) coded to each TDF domain represents the proportion of time across the sample spent discussing barriers and facilitators (both experienced and hypothetical/assumed) within each domain

3.3.3 Intervention Function Extraction

Eight intervention functions were extracted by two independent coders (EG, KW) across 33% of transcripts *(n=7)*. Percent agreement across the seven transcripts was 100%. EG extracted an additional 22 modes of delivery from the remaining 14 transcripts, resulting in an overall total of 30 intervention functions across all 21 transcripts.

3.3.4 Intervention Function Coding

Upon coding, two factors were removed due to lack of specificity, leaving a total of 28 factors. Six factors were coded as multiple intervention functions, resulting in a total of 39 observations. Inter-rater agreement was between "substantial" and "almost perfect" *(Kappa=0.61±0.43*; *PABAK=0.82±0.18*)

Table 2 outlines the number and percent count of factors by intervention function. Of the nine intervention functions indicated by Michie et al. (2014), only four were coded across interviews: *Education, Enablement, Environmental Restructuring, and Modelling*. Across the 29 factors identified as "what" modes of delivery, *Education and Environmental Restructuring* were representative of the most commonly coded factors, accounting for 74.36% of intervention functions coded. Within *Environmental Restructuring,* 11 functions accounted for restructuring the social environment and three functions accounted for restructuring the physical environment.

Table 2

Number and Percent Count of Factors by Intervention Function

Intervention Function	*(n)*	*% total*
Coercion	0	0
Education	15	38.46
Enablement	6	15.38
Environmental Restructuring	14	35.90
Incentivization	0	0
Modelling	4	10.26
Persuasion	0	0
Restriction	0	0
Training	0	0
Total	39	100

3.3.5 Mode of Delivery Extraction

Twenty-nine modes of delivery (13 "how", 16 "who") were extracted by two independent coders (EG, KW) across 33% of transcripts *(n=7)*. Percent agreement across the seven transcripts was 87.8%. EG extracted an additional 48 modes of delivery from the remaining 14 transcripts, resulting in an overall total of 77 modes of delivery (36 "how", 41 "who") across all 21 transcripts.

3.3.6 Mode of Delivery (How) Coding

Upon coding, three "how" factors were removed due to lack of specificity, leaving a total of 33 "how" factors. Eleven factors were coded to multiple categories of the MoDtv0 (Carey et al., 2016), resulting in a total of 45 observations. Inter-rater agreement was indicated between

"substantial" and "almost perfect" *(Kappa=0.77±0.05*; *PABAK=0.92±0.06*). Table 3 presents the number and percent count of modes of delivery identified across MoDtv0 categories.

Table 3

Number and Percent Count of Modes of Delivery by MoDtv0 Category

MOD Category (Top-Level)	***(n)***	**% total** (All Modes of Delivery)	**MOD Category** (Sub-Level 1)	***(n)***	**% total** (Of Top Level)
Digital	22	47%	N/A	N/A	N/A
Human	12	27%	Face-to-Face	8	67%
			Distance	4	33%
Printed Materials	11	24%	Leaflets	4	36%
			Public Notices	2	18%
			Not in Taxonomy	5	45%
Somatic	0	0%	N/A	N/A	N/A
Total	44	100%			

Representing 48% of codes *(n=22)*, digital modes of delivery were identified as a preferred mode of delivery by participants. Almost all participants *(n=16)* who mentioned digital modes of delivery simply referred to the importance of an "online" tool, program, or resource. Therefore, differences between use of a computer or phone were unable to be distinguished. Participants suggested the use of websites, e-mail, video calls, and social media forums (e.g. Facebook) to effectively deliver programs, tools, and resources. Although not included in the taxonomy, online videos were also suggested as effective means for delivery. The use of television for advertisements and commercials was also suggested as an effective mode of delivery.

The use of human interaction represented 27% *(n=12)* of "how" mode of delivery codes. Participants preferred face-to-face delivery *(n=8)* from humans when available, however delivery from a distance *(n=4)* was appreciated as an effective means for individuals who do not live within close proximity of a SCI organization, or lived in rural area where fewer people were available to interact with or fewer support resources were available to use. Face-to-face presentations, although not included in the taxonomy, were also mentioned as a preferred mode of delivery. Examples of distance modes of delivery preferred by participants included the use of audio calls and video calls.

Printed materials as modes of delivery represented 24% *(n=11)* of codes. Of the five items within Sub-Level 1 of the MoDtv0 (2016), only two were coded across interviews: *leaflets (n=4)* and *public notices (n=2)*. Interestingly, the majority of types of printed materials that participants preferred were not included in the taxonomy. Examples include magazines, small blurbs of information (through advertisements or within books), and newsletters.

3.3.7 Intervention Messenger (Who) Themes

Several types of messengers were identified as pivotal for delivering interventions that support individuals aging with SCI. Of the 41 "who" factors extracted, 11 mentioned multiple intervention messengers, resulting in a total of 55 observations. Messengers identified by participants were categorized into two broad themes: individual and organizational. Individual referred to messengers who would be delivering an intervention through a one-on-one interaction. Organizational referred to delivery of a program, tool, and/or resource from an established group or organization.

Twenty-two "who" factors were categorized as individual messengers. Messengers categorized as individual included peers aging with SCI *(n=7)*, family, friends, caregivers *(n=1),* health care professionals *(n=10),* and rehabilitation professionals *(n=4)*. Participants' responses

suggested that health care professionals may be the most preferred individual messenger, followed closely by peers aging with SCI. Specific examples of health care professionals that participants wanted to see as messengers included family doctors, occupational therapists, recreational therapists, and physiotherapists. Numerous medical professionals with different specialties and skills were noted as important messengers due to the variety of issues individuals aging with SCI experience. For example, the participant quoted below mentions examples of health-care providers that she thinks would be most beneficial in a program that would tend to her needs:

> *I think [any type of program] will have to tap into the medical professionals for sure because it kind of depends on what topic it is. You know, a pain doctor who deals with pain management in SCI or the bladder nurse at [name of hospital] could you know answer [bladder-related] questions or um, a physio or a mental health advocate.* (Brenda)

Participants who identified peers aging with SCI as key messengers spoke primarily to the importance of peers playing a large role in informing the content of a program that would be funded, facilitated, and implemented by more wide-scale organizations, such as a SCI organization. Peers were seen as important due to their ability to truly know what someone aging with SCI would need to enhance their participation experiences. An example quote is provided below:

> *I would say [people involved in delivering a program, tool, and/or resource] should be people who have spinal cord injuries. They would know what one would need, or what one should have. It doesn't help much if it's done by people who have no idea on the heights to put certain objects, or how close you can get to something in a wheelchair. There's all sorts of barriers which come up.* (Brian)

Participants felt peer-informed programs presented by SCI organizations would likely be more effective, as SCI organizations would be more likely to both attain more funding for the programs and support more individuals through pre-established client databases. For example, the participant below is speaking to what they would do if they were to work towards developing a program:

> *I mean if I was doing it, I would apply for a grant or something, to the Rick Hansen Foundation or [Name of local rehabilitation centre] or [Name of provincial SCI organization]*, *one of these existing groups that already has the facilities. They have the client database and… it's just uh, start working with a small program, a pilot program, a lot of [the] time you get funding for that. Then you prove the outcome and from there you can develop a program.* (Katie)

Although all participants were a minimum of ten years post-injury, rehabilitation professionals were still considered to be important messengers for programs, tools, and/or resources to support people aging with SCI. Participants felt that individuals who are newly injured should still be educated on issues with aging, therefore providing more of an opportunity to prevent or slow-down any complications or changes. An example quote is provided below:

> *I mean just through a [rehabilitation centre], you know you got a ton of people there from physios to nurses to you know, maybe educating them a bit more on aging and prevention stuff, and um educating the educators, so they can pass on the word, right?* (Alannah)

Thirty-three "who" factors were categorized as organizational messengers. Examples of organizational messengers included SCI organizations *(n=20),* municipal and provincial governments *(n=5)*, community organization groups for other disabilities (e.g. MS Society of Canada, Canadian National Institute for the Blind) *(n=2),* sports organizations *(n=2)*, medical supply companies *(n=2)*, and funding/sponsorship organizations (e.g. Rick Hansen Foundation)

(n=2). All three provincial SCI organizations (i.e. Spinal Cord Injury Alberta, Spinal Cord Injury BC, Spinal Cord Injury Ontario) and one national (i.e. SCI Canada) represented 61% of all organizational messengers. Additionally, the other types of organizational messengers identified aside from medical supply companies and municipal/provincial governments, were mentioned in affiliation with a SCI organization. As presented in the quote below, participants felt that SCI organizations would allow for a more stable platform for any program, tool and/or resource to be implemented:

> *Would be nice if somebody like [Name of provincial SCI organization] put [a program] together, because that gives you an anchor. Because almost anything I've known needs an anchor.* (Logan)

Participants felt that SCI organizations would be able to enhance the effectiveness of any programs, tools, and/or resources by working in partnership with individuals aging with SCI, medical professionals and other disability groups. For example, the participant below is speaking to the importance of involving numerous groups together getting together to develop and implement a program:

> *SCI groups, health care professionals. I've been involved with [numerous disability foundations] for 30 years; in the main sense… all of them other disability foundations, our mandate is get people out and active and you know still some people say, "Oh, [name of disability foundation], what's that?" … and we've been around for 30 years. So, you get, you know a wide range of people involved in creating what is created and get participation from everybody so they take partial ownership maybe and promote it.* (Dean)

Municipal and provincial governments represented the second most preferred organizational messengers identified by participants. In a similar fashion to SCI organizations, municipal governments were identified as key messengers to ensure any programs, tools, and/or resources are able to reach as many people within a community as possible. For example, the participant below is speaking to the importance of having a resource promoted at the municipal level if they happen to move to a new city while getting older:

> *I'm just thinking, if you were new to [a city], like if I'm going to move somewhere, I'm either going to find [resources] this stuff from peers in that community, or you know maybe at uh… yeah at the municipal or city level… So, you know what, in saying that, I'd like to see our [adapted] programs in the municipal parks and recreation resources materials.* (Sarah)

Conversely, mentions of provincial governments as messengers were often associated with their ability to fund programs, tools, and/or resources. For example, the participant below is speaking to how they feel that regardless of the program, the provincial government would have to somehow be involved due to their capacity for funding through various means:

> *Yeah, you'd have to get [someone from the government] involved. Going through either the Ministry of Health or [province-specific disability support program], which covers say the cost of repairing wheelchairs. But something would eventually probably trickle onto the Ministry of Health.* (Christopher)

Interestingly, the mention of medical supply companies was also accompanied by feelings of worry, as participants felt companies would not be willing to say anything negative about their products. For example, the participant below is speaking to the importance of peers who have

actually used a heavily promoted piece of medical equipment to be able to share their experiences with the product:

> *You would well, because I mean you would think that you'd want somebody who was in the industry who maybe knew other people who have tried that uh [new] product and whether there were any problems with it. I mean it's tough to just go by the uh uh manufacturer cause of course they're not going to say anything negative.* (Jeremy)

3.4 Results: Behavioural Analysis

Based on the findings from barrier and facilitator extraction and coding, *ECR, Skills, and Social Influences* were identified as the most prevalent and meaningful TDF domains. Therefore, in terms of the COM-B model, *physical capability, physical opportunity, and social opportunity* were identified as the factors that need to be changed in order for participation to be enhanced in individuals aging with SCI.

3.4.1 Identification of Intervention Functions and Policy Categories

Specific to the COM-B components identified above, intervention functions relevant to *physical capability* include *training* (i.e. imparting skills) and *enablement* (i.e. increasing means/reducing barriers to increase capability or opportunity). Intervention functions relevant to *physical opportunity* include *training*, *restriction* (i.e. increase the target behaviour by reducing the opportunity to engage in competing behaviours), *environmental restructuring* (i.e. changing the physical or social context), and *enablement*. Intervention functions relevant to *social opportunity* include *restriction*, *environmental restructuring, modelling* (i.e. providing an example for people to aspire or imitate), and *enablement.*

Specific to findings from intervention function extraction and coding, *education* (i.e. increasing knowledge or understanding)*, environmental restructuring, enablement, and modelling* were identified as the most prevalent and meaningful TDF domains. Therefore, six of nine intervention functions (persuasion, incentivization, and coercion were excluded) were identified as relevant intervention functions for intervention design and implementation.

Based on the identified intervention functions mapped against policy categories (see Figure 6, Appendix I), all policy categories can be considered as viable options to support the delivery of an intervention that supports individuals aging with a SCI.

3.5 Results: Developing Recommendations

EG presented all initial findings from abductive analyses in a meeting with HG and all three SCI organization representatives. All three representatives felt that the findings from both inductive and deductive analyses were relevant and useful to each of their respective organizations. Therefore, no modification or additional analyses were undertaken.

Specific to behavioural analyses, EG presented the finding that six intervention functions and all policy categories were viable options to support the delivery of an intervention that supports individuals aging with SCI. Each representative then spoke to the capacity of their respective organizations to be able to develop and implement each type of proposed intervention function and corresponding policy categories. Suggestions for intervention recommendations continued to be developed and modified throughout the discussion. The final four recommendations decided upon during the meeting included:

1) *Educate and Build Capacity among SCI Organization Staff:* The organizations' representatives wanted to ensure staff, including peer mentors, were prepared to discuss with and support people aging with SCI. In particular, they wanted staff to understand

meanings of successful aging, barriers to social participation, and knowledge and supports needed by people aging with SCI.

2) *Educate and Build Capacity Among Clients/Membership*: The organizations' representatives wanted to ensure their clients with SCI received information and supports regarding meanings of successful aging, as well as knowledge and supports that address barriers and promote social participation among individuals aging with a SCI.
3) *Advocate to and Educate the Government About People Aging with SCI:* The organizations' representatives felt that the use of the scientific evidence in this thesis that is informed from a first-hand perspective may be valuable in both advocating to and educating the government about the needs of individuals aging with SCI. If the government is made aware of these needs, there is an enhanced likelihood that the government may be able to start implementing changes to legislature that would be beneficial to individuals aging with a SCI (e.g., addressing challenges with mobility devices).
4) *Partner with Other Organizations (e.g. other disability organizations) to create tools and resources and advocate:* Each organization's representative felt that working in partnership with other organizations both within and outside the SCI community would increase their overall capacity to create further tools and resources, as well as their capacity to advocate on behalf of the members of each organization.

The organization representatives felt that in order to achieve these recommendations, the development of both a high-level and concise report, as well as a webinar summarizing the results of this thesis would be effective means for achieving each recommendation. Both the report and webinar were viewed as "important initial conversation pieces" to allow for changes to be made at both the individual and organizational level. All APEASE criteria (Michie et al., 2014) were

met, as all representatives felt that the recommendations were affordable, practical, effective, acceptable, safe, and equitable to implement using a webinar and concise report.

4 Discussion

Recommendations for interventions designed to support people aging with SCI were co-developed with input from researchers, SCI community organizations, and individuals with lived experience of aging with SCI. Adoption of an IKT and pragmatic approach, along with the use of abductive analyses contributed to development of the recommendations. Findings from this thesis address all three steps of the behaviour change intervention design process as outlined by Michie et al. (2014) (i.e. understanding the behaviour, identifying intervention options, and identifying content and implementation options) and will be discussed alongside their corresponding stage of intervention design.

4.1 Stage 1: Understanding the Behaviour

To further understand participation behaviours in the context of aging and SCI, this thesis aimed to explore meanings of successful aging with SCI and identify barriers and facilitators to participation from the perspectives of people with lived experience of aging with SCI. Our findings suggest that successful aging with SCI can be defined as an interconnected and multi-faceted concept that emphasizes equal importance of overall health and well-being, independence, and social participation. Meaningful barriers to participation were categorized as intrapersonal (i.e. intrapersonal emotional distress, aging-related complications), interpersonal (i.e. lack of aging and SCI-specific resources/knowledge), and environmental (i.e. frustrations with community priorities). Acting as a proactive self-advocate, being prepared and aware for the challenges of aging, and continuing to develop and maintain strong support systems were seen as facilitators that could enhance participation while aging with SCI.

4.1.1 Successful Aging and Participation

This thesis contributes to the literature by expanding upon previous attempts to define and understand successful aging in a more inclusive manner for individuals living with physical disabilities (Molton & Yorkston, 2017; Pruchno et al., 2010; Yorkston et al., 2010; Young et al., 2009). While previous work has acknowledged the importance of incorporating subjective criteria and integration of physical, mental, and social domains of health to understand successful aging, these models have excluded the perspectives of individuals living with long-term disabilities (Pruchno et al., 2010; Young et al., 2009). This thesis addresses these limitations by accounting for the perspectives of individuals with lived experience of a long-term SCI.

Our co-developed themes both align and challenge findings from previous focus group studies that aimed to understand successful aging in the context of numerous physical disabilities (e.g., multiple sclerosis, post-polio syndrome, muscular dystrophy) (Molton & Yorkston, 2017; Yorkston et al., 2010). In reference to the first focus group study (Yorkston et al., 2010), two themes (*physical pathways: progression of physical systems* and *concerns about the future: participant uncertainty*) aligned with our sub-themes of aging-related complications and intrapersonal emotional distress, respectively. Conversely, Yorkston et al.'s (2010) theme of *changing health care: reflecting improvement noted over time* was not consistent with our findings, as our participants indicated frustration with changing health care due to over-allocation of resources to the general population and a lack of interest/knowledge shown by health care professionals when treating people aging with SCI. Our findings align with three identified themes from the more recent focus group study (Molton & Yorkston, 2017): [1] *the importance of autonomy and choice in decision making* (aligns with maintenance of independence), [2] *social and community participation and positive connection to others* (aligns with

improvement/maintenance of social participation and having strong support systems), and [3] *accessible, appropriate, and available medical care* (aligns with lack of aging and SCI-specific resources/knowledge). However, differences were also present as two themes specific to the second focus group (psychological resilience, psychological adaptability) did not arise from our findings. Notable differences suggest that previous research may not address unique topics to aging and SCI, as both focus groups were inclusive of participants with physical disabilities other than SCI. Additionally, differences in data collection methods may also contribute to differences across findings. This thesis contributes to the literature by providing an in-depth understanding of successful aging with SCI in the context of participation.

Findings from our developed themes support that participation may be an ideal target behaviour for promoting successful aging to people with SCI. Our findings also suggest that the quality of one's participation experiences may be an important focus for intervention development, as themes of quality participation as developed by Martin Ginis and colleagues (2017) closely aligned with our findings. For example, within our theme of improving/maintaining social participation, feelings of *belongingness* (e.g. feeling like a valued member of their sports team or volunteer groups), *meaning* (e.g. working towards developing new advocacy committees), *engagement* (e.g. continuing to be motivated to participate in everyday task and activities), *mastery* (e.g. successfully being able to complete everyday tasks and activities), and *challenge* (e.g. attempting new leisure activities at an older age) appeared to be important for participants. Within our theme of maintaining independence, *autonomy* (e.g. being able to make your own choices) was also something mentioned as important by participants. Given these similarities, it appears that future behaviour change interventions may want to focus on improving the *quality* of one's participation behaviours to promote successful aging with SCI.

4.1.2 Barriers and Facilitators to Participation

While 11 of 14 TDF domains were identified as relevant to barriers and facilitators of participation, *ECR, Skills, and Social Influences* were recognized as the most influential TDF domains. Specifically, *ECR* was influential to both barriers and facilitators, *Skills* was influential to barriers, and *Social Influences* was influential to facilitators. Further use of the BCW revealed that *physical capability, physical opportunity,* and *social opportunity* were relevant COM-B components to target in an intervention. Interestingly, both *automatic* and *reflective motivation* were not considered as relevant COM-B components in this thesis, suggesting that participants may already be motivated to participate in society as they age. This finding has future implications for selecting behaviour change theories, which may help guide the development of future interventions. As it stands, numerous behaviour change theories that are central to intervention development primarily focus on the constructs of intention and reflective motivation (Gainforth, West, et al., 2015). However, our data suggests that intervention designers may need to select theories that address broader social and ecological factors (e.g. self-determination theory, social-ecological model) that can influence behaviour.

To the best of our knowledge, three studies have adopted use of the TDF to understand barriers and facilitators to behaviour change in people living with SCI (Bérubé et al., 2015; Munce et al., 2014; Tomasone et al., 2017). However, only one study completed a behavioural analysis beyond identification of relevant TDF domains (i.e. Bérubé et al., 2015). Bérubé et al. (2015) aimed to understand health care professionals' (e.g. SCI nurses, orthopaedic spine surgeons) opinions on barriers and facilitators to implement evidence-based guidelines for early management of adults with traumatic SCI. Although 10 TDF domains were initially identified, only six were seen as relevant (*ECR, Knowledge, Skills, Beliefs about Capabilities, Belief about Consequences,*

and *Social Influences*). Further use of the BCW indicated all six COM-B components were relevant targets for intervention. As behaviour change is context dependent (Michie et al., 2014), differences in selection of COM-B components may be attributed to differences across research questions, target populations, and target behaviours.

Our findings also indicate that domains from both versions may be relevant to intervention design. Although Cane et al. (2012) was used as the guiding framework for this thesis, *Nature of the Behaviour*, a domain unique to the initial version of the TDF, was coded numerous times across experienced facilitators. Our findings suggest that already engaging in a participation behaviour plays a large role in allowing for continuation of that same behaviour. *Nature of the Behaviour* was also previously identified by Tomasone et al., (2017) as a relevant TDF domain to maintain participation in a telephone-based physical activity counselling service for individuals with physical disabilities. These similarities suggest that domains from both TDF versions may be relevant when understanding behaviours in the SCI population. Although further research is needed to comprehensively understand use of the TDF in the SCI population, it may be valuable to consider the use of both versions when developing behaviour change interventions.

4.2 Stage 2: Intervention Options

The intervention functions of *training, enablement, restriction, environmental restructuring, modelling,* and *education* were deemed relevant to promoting participation among individuals aging with a SCI. As such, all policy categories would be able to support delivery of the six intervention functions.

The BCW has not previously been used to develop interventions to enhance participation in people aging with SCI. However, the wide variety of intervention functions identified in our findings align with previous efforts to disseminate knowledge and change physical activity

behaviours in the SCI community (Arbour-Nicitopoulos et al., 2013; Gainforth, Latimer-Cheung, Athanasopoulos, & Martin Ginis, 2013; Latimer-Cheung et al., 2013; Sweet, Martin Ginis, Estabrooks, & Latimer-Cheung, 2014). SCI Action Canada, a network of researchers and community partners aiming to initiate and maintain physically active lifestyles for people with SCI (Martin Ginis et al., 2012), developed evidence-based physical activity guidelines for people with SCI (Martin Ginis et al., 2011). In order to disseminate these guidelines, a variety of efforts were undertaken such as the development of an informational toolkit (Arbour-Nicitopoulos et al., 2013), a telephone-based counselling and peer-mediated home-based physical activity program (Latimer-Cheung et al., 2013), and further promotion of these resources through province-wide knowledge mobilization initiatives (Gainforth et al., 2013). Across these efforts, numerous intervention functions and policy categories were targeted to improve overall impact of the guidelines on improving physical activity in SCI communities. As such, effectively supporting people aging with SCI may also require the development of multiple, multi-faceted interventions that target several different intervention functions and policy categories.

4.3 Stage 3: Identify Content and Implementation Options

Our findings suggest there a variety of intervention messengers and modes of delivery that may be viable options to consider when designing interventions to support people aging with SCI.

4.3.1 Intervention Messengers

With respect to individual messengers, the identification of peers, health care professionals, rehabilitation professionals, and family and friends as intervention messengers is consistent with previous research that identified messengers for delivering health and physical activity information for individuals living with SCI (Faulkner et al., 2010; Letts et al., 2011). In terms of organizational

messengers, SCI community organizations have previously been identified as key messengers due to their extended reach through media supports and peer groups (Letts et al., 2011). The identification of [1] maintaining physical health and [2] participation in leisure and recreation activities as participation behaviours according to the Participation in Daily Activities Questionnaire (PDAQ) (Noreau et al., 2013) may explain to the noted similarities between this thesis and previous research. Moreover, these findings suggest that current individual messengers of health and physical activity information may show promise as messengers for interventions designed to support people aging with a SCI.

This thesis also contributes to the literature through the identification of municipal and provincial governments as key organizational messengers, as participants felt that municipal governments may enhance a community organization's overall capacity to deliver interventions, and provincial governments may enhance the effectiveness of interventions through the provision of additional financial support. Our government-specific findings provide evidence-based rationale for SCI organizations to contact municipal and provincial governments for their support in the development of future interventions. This thesis also contributes to the literature through the suggestion for SCI organizations to work in partnership with other organizations (i.e. other disability organizations, medical supply companies, and funding/sponsorship organizations) to build upon their current capacity to deliver interventions through the provision of additional financial and practical support from the external organizations. One reason for participants suggesting involvement with other organizations may be due to participants' high and meaningful levels of community involvement. Participants in previous research studies may not have been as heavily involved with other organizations or may have felt that organizations would not be beneficial in supporting delivery of health and physical activity information. Despite several of

our findings aligning with previous research, differences across findings enforce the importance of tailoring the selection of intervention messengers to the needs and preferences of the specific target population.

4.3.2 Intervention Modes of Delivery

A wide variety of modes of delivery (i.e. "how" components) were identified, aligning with the previous research noted above (Faulkner et al., 2010; Letts et al., 2011). Examples of modes of delivery identified across all three studies include use of internet (e.g., e-mail), videos, and brochures/leaflets. As emphasis on the importance of using various modes of delivery continues to be a consistent finding, this thesis reinforces the importance of tailoring the selection of implementation options to the needs and preferences to the selected target population.

Despite the similarities explained above, there are notable differences between our findings and previous research. For instance, DVDs and memory sticks were previously identified as preferred methods of delivery (Faulkner et al., 2010; Letts et al., 2011). In addition, neither study mentioned the importance of smart phones in accessing the internet. However, use of smart phones was a frequent response across our findings. These differences are not surprising, as technology continues to rapidly develop, and previous research was conducted seven to eight years ago. These differences suggest that research examining modes of delivery may need to be conducted more frequently to account for continuous and rapid advancements in technology.

4.4 Diversity of Findings

Across all stages of intervention design, conflicting ideas and views almost always arose within each of our developed themes. Specifically, differences in responses were often attributed to a person's place of residence (i.e. urban or rural area), type of residence (i.e. living in your own

home or living in a long-term care facility), age (e.g. differences between someone who is 45 years old compared to someone who is 75 years old), and type of injury/mode of mobility (e.g. a high-level injury where the use of a power wheelchair is required compared to someone who walks independently). The diversity and heterogeneity of responses within themes may be attributed to the diversity and heterogeneity of both a SCI itself, as well as each individual's personal experiences with aging. The diversity of ways in which a person can experience a SCI will ultimately impact any subsequent physiological, psychological, or lifestyle changes they may experience, regardless of biological aging. Our findings suggest that interventions designed to address the needs of individuals aging with SCI may need to be specified based on parameters such as a person's age, level/type of injury, and/or mode of mobility.

4.5 Development of Recommendations

To further synthesize and implement the findings within this thesis, four recommendations were put forth in partnership: [1] *Educate and Build Capacity Among SCI Staff*, [2] *Educate and Build Capacity Among Clients/Membership*, [3] *Advocate to and Educate the Government*, and [4] *Partner with Other Disability Organizations to Create Tools and Resources and Advocate*. Our community partners indicated these recommendations could be implemented as they met Michie et al.'s APEASE (affordable, practical, effective, acceptable, safe, and equitable) criteria (2014) and could be disseminated through both a written report and webinar.

Within these recommendations, our findings are synthesized with respect to each stage of intervention development. As recommendations of this nature have not previously been developed for aging and SCI, findings from this thesis provide evidence-based rationale for the development of these specific recommendations. First, each recommendation addresses five of our identified intervention functions: *Education*, *Training, Modelling, Environmental Restructuring,* and

Enablement. With respect to policy categories, our recommendations address three policy categories deemed feasible by our community partners (*Communication/Marketing, Environmental/Social Planning, Service Provision)*. Each recommendation also involves important intervention messengers as indicated by our participants including SCI organizations, peers aging with SCI, governments, and other disability organizations. Finally, the use of multiple modes of delivery is ensured through dissemination of *both* a written report and webinar.

4.6 Future Directions

The recommendations developed in this thesis are not a solution, but a first step to addressing the needs of individuals aging with SCI. Further work is required to develop our intervention recommendations into real-world behaviour change interventions. At this stage of intervention design, our community partners recommended achievement of the four recommendations throughout the development of a concise written report and a webinar to share among the intended audiences. As interventions are developed, future research endeavours can assess proposed interventions in terms of efficacy, effectiveness, and fidelity.

Our findings from both inductive and deductive analyses provide recommendations for future studies aiming to further investigate aging with a SCI. Our theme of Successful Aging is an Interconnected and Multi-Faceted Concept is representative of a definition of successful aging informed by the perspectives of individuals aging with a long-term SCI. Further research could determine if our theme is also representative of a successful aging framework specific to individuals aging with long-term SCI. Also, the heterogeneity of responses found across our interviews provides scientific rationale for future research across numerous topics including but not limited to health (e.g. menopause and SCI) and policy (e.g. community accessibility). In addition, the variance in responses due to factors such as age, level of injury, and mode of mobility

provides scientific rationale for future studies to be conducted within the context of a specific demographic characteristic.

With respect to future policy, findings from this thesis have the potential to play an important role for both municipal and provincial governments. As the baby boomer generation ages and people are living longer than ever before, gerontology and policy research must continue to investigate strategies governments can adopt to accommodate the rapidly aging population (e.g. Anderson & Hussey, 2000; Knickman & Snell, 2002). Findings from this thesis provide valuable, evidence-based information that policy makers can use to ensure the needs of individuals aging with a long-term SCI are prioritized alongside the needs of the general population.

4.7 Strengths

One of the strengths of this thesis is the comprehensive use of behaviour change theory and frameworks. Overall, the use of theory allows for a systematic approach for intervention development that may enhance the likelihood of effectiveness and replicability for future interventions (Gainforth, West, et al., 2015; Michie et al., 2016, 2014). By using the BCW and the TDF, we were able to harness strengths of several behaviour change theories and frameworks, which the use of one single theory would not permit (Cane et al., 2012; Michie et al., 2014).

Another notable strength of this thesis is the adoption of an IKT approach. Throughout the development phase, this approach allowed for further refinement and tailoring of our research question. During recruitment, the credibility and reach of the SCI organizations contributed to a large and heterogeneous sample size. Throughout analyses, the SCI organizations enhanced both the quality and relevance of our findings by acting as additional critical friends throughout theme development and ensuring our findings were continuing to address the changing needs of each respective organization. Finally, and perhaps most importantly, engaging community

organizations from the beginning of the research process enhances the overall potential of this thesis with respect to ensuring research is used in practice. Throughout and beyond the research process, the partnership between researchers and community organizations has only continued to strengthen, and has led to plans for the future development of several knowledge tools and products (e.g., written report, webinar) to be implemented across all three organizations.

Finally, the selection of pragmatism as an approach to this thesis is a notable strength. Being an IKT researcher, the main priority of this thesis was the development of knowledge tools that are useful for and relevant to people aging with SCI (Kothari & Wathen, 2013). Aligning with IKT principles, pragmatism is grounded in prioritization of the research question and the creation of tangible recommendations (Coppola et al., 2018; Feilzer, 2010; Onwuegbuzie & Leech, 2005). Approaching this thesis with a pragmatic lens provides rationale for the selection of abductive analyses, which ultimately allowed for the interview transcripts to be analyzed with more depth and breadth than the selection of solely inductive or solely deductive analyses. In addition, pragmatism promotes collaboration among researchers and community partners, regardless of philosophical assumptions (Onwuegbuzie & Leech, 2005).

4.8 Limitations

As with any research study, there are limitations that need to be addressed. Despite our best efforts with recruitment, certain participants within our selected demographic parameters were not represented in our sample. Specifically, our sample does not include people who identify as females over the age of 65, and people over the age of 65 with either a cervical or lumbar-level injury. However, this limitation also results in an important future recommendation. If SCI community organizations were unable to recruit these groups despite having prominent reach within SCI communities, current and future research endeavours may also exclude these groups.

Moreover, this limitation suggests that future research endeavours are needed to understand groups that are not represented in this thesis.

Another limitation of this thesis is the lack of initial demographic data from participants on marital status. Upon realization, this limitation was worrisome as marital status has previously been shown to impact life satisfaction, well-being, and quality of life in people living with SCI, regardless of age (Holicky & Charlifue, 1999; Kalpakjian et al., 2011; Post, de Witte, van Asbeck, van Dijk, & Schrijvers, 1998). In order to address this limitation, probing questions were used to inquire about participants' marital status. Overall, a majority of participants spoke to their marital status with respect to their prominent roles for the provision of emotional and practical support. Further research is needed to understand the intersection of marital status as people age with SCI.

The selection of HG as EG's critical friend during the inductive thematic analysis is also a limitation of this thesis. As HG was EG's thesis supervisor, the developed codes and themes were likely influenced by the power dynamic between a supervisor and student. For future research endeavours, it may be valuable to select a critical friend who has a more neutral relationship with the researcher leading the analysis.

Although use of the TDF to categorize and understand barriers and facilitators is viewed as a strength, use of the TDF also comes with limitations. Specifically, the TDF is not a theory as initial mechanisms of change from theories that inform the framework are not specified (Nilsen, 2015). Therefore, use of the TDF does not provide an explanation for how identified domains are connected to one another or ways in which domains can influence one another. This may pose difficulties when trying to develop theory-based interventions and to further understand identified TDF domains in a variety of contexts.

With respect to TDF domains and implementation options (i.e. messengers and modes of delivery) frequency counts were used. Although certain items were mentioned a limited number of times, it is important to note that a lack of frequency of a domain or option may not equate to a lack of importance. Therefore, further interpretation of identified domains or implementation options beyond frequency counts would need to be undertaken before selection of relevant items for intervention development and implementation. Future research endeavours may want to consider conducting a formal ranking or rating exercise to provide evidence-based rationale behind the selection of relevant TDF domains, messengers, and modes of delivery.

5 Conclusion

This thesis is the first adoption of an IKT approach to develop theory-informed recommendations for interventions designed to support individuals aging with SCI. Inductive analyses provided insight into meanings and experiences of successful aging. Successful aging was defined as an interconnected and multi-faceted concept, and is stopped by a variety of intrapersonal, interpersonal, and environmental barriers. Deductive analyses revealed that a number of intervention functions, messengers, and modes of delivery are needed to develop interventions that support people aging with SCI. Together, findings from both analyses indicate that multiple interventions in various formats are needed to support people aging with SCI. Continued efforts are needed to ensure these findings are translated in partnership with SCI organizations and lead to tangible, positive changes for people aging with SCI.

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Appendices

Appendix A: Initial Letter of Contact

THE UNIVERSITY OF BRITISH COLUMBIA

Re: Opportunity to Participate in Research – Study on Aging with a Spinal Cord Injury
Dear (Insert Participant's Name Here),

Research Study: Developing Theory-Based Recommendations for Tools, Resources and Programs Designed to Enhance Participation in Individuals Aging with a Spinal Cord Injury (SCI)

Dr. Heather Gainforth is the principal investigator of this research study. Dr. Gainforth is an Assistant Professor in the School of Health and Exercise Sciences at the University of British Columbia Okanagan and Director of the Applied Behaviour Change (ABC) Lab.

We have partnered with her lab to further understand participation in individuals aging with a spinal cord injury (SCI). Findings from this study will be used to inform recommendations for resources, programs or tools that will aim to enhance participation in individuals aging with a SCI. You will receive $20 to the retailer of your choice from one of the following retailers (i.e. Starbucks, Tim Hortons, Cineplex, Bath and Body Works, Best Buy) for your participation in this study. The research team will aim to send your gift card to you within three weeks of participating in the study. For further information about the study or to arrange for your participation, please contact Emily Giroux at **abc.lab@ubc.ca** or 866-835-8979 (Mailbox #: 91042).. .
Participation in the study is entirely voluntary. If you choose to not participate, your involvement with SCI (Alberta, BC, Ontario) will not be affected or change in any way.

Sincerely,

If SCI Ontario:
Sheila Casemore, Senior Manager
Spinal Cord Injury Ontario

If SCI BC:
Chris McBride, Executive Director
Spinal Cord Injury BC

If SCI Alberta:

Teren Clarke, Chief Exercutive Officer
Spinal Cord Injury Alberta

Emily Giroux, Research Assistant
University of British Columbia Okanagan

Dr. Heather Gainforth, Assistant Professor
University of British Columbia Okanagan

Appendix B: Written Letter & Social Media for Participant Recruitment

EMAIL TO BE SENT BY PARTNER ORGANIZATIONS - GENERAL

Subject: Participants Needed – Study on Aging with a Spinal Cord Injury

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SCI Alberta, SCI BC and SCI Ontario have partnered with Dr. Heather Gainforth, an Assistant Professor at the University of British Columbia Okanagan, to conduct a study aimed at further understanding participation in individuals aging with a spinal cord injury (SCI).

You are receiving this email because you are an individual that has begun aging with a long-term spinal cord injury. Your email address was obtained from [Insert 1 of 3 SCI Organizations HERE].

We are recruiting individuals who are currently aging with a SCI. The research team is aiming to develop tools, resources or programs designed to improve participation in individuals aging with a SCI. Results from this study will help to inform the recommendations and will be the first step to developing and implementing these types of tools, resources or programs.

If you choose to participate in this study, you would take part in an audio-recorded interview that will take approximately **60-90 minutes.** Before the interview, you will be asked to fill-out a pre-interview survey that includes questions about your demographic information and contact information in order for the research team to contact you in the future. This pre-interview survey will take approximately **10 minutes** to complete.

To be able to take part in this study, you must:

- Be affiliated with either **SCI Alberta, BC or Ontario**
- Be at least **45** years of age
- Be at least **10** years post-injury
- **Not** be diagnosed with an age-related condition that impacts cognitive function (e.g. Dementia, Alzheimer's Disease)

You will receive $20 to one of following retailers of your choice (i.e. Starbucks, Tim Hortons, Best Buy, Cineplex, Bath and Body Works) for participating in the audio-recorded interview. Your interview will be scheduled based on times that work best for you.

If you are interested in participating, please click on the following link:

https://survey.ubc.ca/s/agingSCIstudy/

Clicking on the link above will direct you to an online consent form. Please read the consent form in its entirety as it will outline all study details (e.g. time commitment, inclusion criteria, nature of the study). If you agree to consent, you will then be further linked to a pre-interview survey that will ask you to provide simple demographic and contact information.

If you would prefer to contact the research team by phone, you may leave a voicemail message at 866-835-8979 (Mailbox #: 91042)**.** The research team will return your phone call within 7 business days to allow you to complete the pre-interview questionnaire over the phone.

If you have any questions about the study, please contact Emily Giroux at abc.lab@ubc.ca or 866-835-8979 (Mailbox #: 91042).

SOCIAL MEDIA TO BE POSTED BY PARTNER ORGANIZATIONS

We have partnered with UBC to conduct a study on Participation in Individuals Aging with a Spinal Cord Injury. Receive $20 to participate. For info: LINK

****The blurb will link to the recruitment letter or directly to consent form****

Social Media Blurb: (Blurb was posted as either a Facebook post, Twitter post, posting within a weekly/monthly newsletter sent out by 1 of the 3 SCI Organizations)

Appendix C: Ethics Approval

The University of British Columbia Okanagan
Research Services
Behavioural Research Ethics Board
3333 University Way
Kelowna, BC V1V 1V7

Phone: 250-807-8832
Fax: 250-807-8438

CERTIFICATE OF APPROVAL - MINIMAL RISK

PRINCIPAL INVESTIGATOR:	INSTITUTION / DEPARTMENT:	UBC BREB NUMBER:
Heather Gainforth	UBC/UBCO Health & Social Development/UBCO Health and Exercise Sciences	H17-02426

INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:

Institution	Site
UBC	Okanagan

CO-INVESTIGATOR(S):
Emily Giroux

SPONSORING AGENCIES:
Michael Smith Foundation for Health Research - "Improving the Implementation and Impact of Evidence-based Health Promotion Interventions in Real World Settings"
UBC Okanagan Office of the Provost - "Start Up Funding"

PROJECT TITLE:
Developing Theory-Based Recommendations for Tools, Resources and Programs Designed to Enhance Participation in Individuals Aging with a Spinal Cord Injury (SCI)

CERTIFICATE EXPIRY DATE: November 6, 2018

DOCUMENTS INCLUDED IN THIS APPROVAL: **DATE APPROVED: November 6, 2017**

Document Name	Version	Date
Protocol:		
Aging & SCI - MSc. Research Proposal	1	September 16, 2017
Consent Forms:		
Aging & SCI - Consent Form	1	October 30, 2017
Advertisements:		
Aging & SCI - Recruitment Materials	1	October 30, 2017
Questionnaire, Questionnaire Cover Letter, Tests:		
Aging & SCI - Contact Info Survey	1	September 29, 2017
Aging & SCI - Interview Guide/Script	1	September 30, 2017
Aging & SCI - Pre-Interview Questionnaire	1	October 30, 2017
Letter of Initial Contact:		
Aging & SCI - Initial Letter of Contact	1	October 30, 2017
Other:		
https://survey.ubc.ca/s/agingSCIstudy/		

The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

Appendix D: Consent Form

THE UNIVERSITY OF BRITISH COLUMBIA

Consent Form
Developing Theory-Based Recommendations for Tools, Resources and Programs Designed to Enhance Participation in Individuals Aging with a Spinal Cord Injury (SCI)

Principal Investigator: **Dr. Heather Gainforth**
Assistant Professor
School of Health and Exercise Sciences, University of British Columbia Okanagan
Phone: (250) 807–9352;
Email: heather.gainforth@ubc.ca

Co-Investigators: **Emily Giroux**
MSc. Student
School of Health and Exercise Sciences, University of British Columbia Okanagan
Email: emily.giroux@ubc.ca

Purpose: The purpose of this study is to develop a first-hand understanding of experiences of participation in individuals aging with a spinal cord injury (SCI). This research study aims to work with SCI Alberta, SCI BC and SCI Ontario to develop recommendations for tools, resources or programs designed to enhance participation in individuals aging with a SCI. You are being invited to take part in this research because you are a person who is currently aging with a SCI (i.e. minimum 45 years of age, minimum of 10 years post-injury, affiliated with Spinal Cord Injury BC, Ontario or Alberta). You are not eligible to participate in this study if you do not meet the criteria. You are also not eligible if you have been formally diagnosed with an age-related cognitive disorder (e.g. Alzheimer's Disease, dementia).

Study Procedures: For this study, you will be asked to complete an online contact information survey and an interview with a member of the research team. The online survey will ask for demographic information and basic contact information to allow a member of the research team to contact you to schedule a convenient time for an interview. The pre-interview survey is estimated to take 10 minutes to complete. At the time of the interview before beginning to answer any questions, you will be asked to consent verbally to participating in the interview, as well as having the interview be audio-recorded by the researcher who is conducting the interview with you. You will have the option to once again hear the components of the consent form before the

interview begins. You will be asked a series of questions that will relate to your personal experiences while aging with a SCI, any barriers or facilitators to participation that you may have experienced while aging with a SCI, and any components you would like to see in a tool, resource or program designed to support participation while aging with a SCI. In total, the interview should take approximately 60-90 minutes to complete.

Potential Risks: There are no known physical, psychological, economic, or social risks associated with this study. You should not feel obliged to answer any material or participate in anything that you find objectionable or that makes you feel uncomfortable. You may also withdraw from the study at any time by contacting Dr. Gainforth by phone or by email.

Potential Benefits: Your participation in this study will allow for a better understanding of the experiences of participation from the perspective of individuals aging with a SCI, as well as provide information about the important components to consider when designing tools, programs or resources to support participation in people aging with a SCI. Findings from this study will help to inform how we can develop tools, resources or programs designed to enhance participation in individuals aging with a SCI. Findings from this study have the potential to make a significant contribution to the lives of individuals aging with a SCI.

Confidentiality: This online questionnaire is administered by the UBC-hosted version of FluidSurveys. All data will be stored and backed up in Canada. All information provided will be kept strictly confidential. Electronic survey data will be stored in password-protected files on a password-protected computer in Dr. Gainforth's Lab at UBC Okanagan. All paper records will be stored in a locked cabinet in Dr. Gainforth's Lab at UBC Okanagan for a minimum of 5 years following publication. As this study is being completed for a thesis project, thesis documents will be published on ciRcle: UBC's repository for research and teaching materials. Additionally, the data from this study may be published in professional journals or presented at scientific conferences. However, any such thesis documents, publications or presentations will be of general findings only and will never breach your confidentiality. Non-identifiable data will be shared directly with the community in the form of presentations and/or reports. Participants may contact the research team if interested in obtaining a copy of the report or attending a presentation.

Compensation: You will receive a $20 gift card to one of the following retailers (i.e. Starbucks, Tim Hortons, Cineplex, Bath and Body Works, Best Buy) for participating in this study. You will be able to indicate how you would like to receive your gift card (i.e. by mail or by e-mail) in the online contact survey that will be filled out before the interview. We aim to ensure you receive your gift card within three weeks of completing the study.

Contact for information about the study: If you have any inquiries or would like further information in regards to this study, you may contact Dr. Heather Gainforth at (250) 807–9352. If you require information and reside outside of British Columbia, please feel free to email at heather.gainforth@ubc.ca or abc.lab@ubc.ca.

Contact for concerns about the rights of research subjects: If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Services at 1-877-822-8598 or the UBC Okanagan Research Services Office at 250-807-8832. It

is also possible to contact the Research Participant Complaint Line by e-mail (RSIL@ors.ubc.ca). Please reference the study number (H17-02426) when contacting the Complaint Line so the staff can better assist you.

Consent: Your participation in this study is completely voluntary and you are free to not answer any of the questions. You may withdraw from this study at any time without any consequences by merely exiting the pre-interview survey by closing your browser, or letting a member of the research team know you wish to withdraw at any point during your interview. Additionally, you can email Dr. Gainforth to withdraw after completion of the interview and have your data removed from the study.

If you would like to participate, please click on the "next page" button to begin. This will indicate that you have read and understood the above information and have consented to participate in this study. If you do not wish to participate, please exit this website.

Appendix E: Interview Guide

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Interview Guide: Enhancing Participation in Individuals Aging with a Spinal Cord Injury

Introduction for participants who have previously filled out the pre-interview survey:
Before we begin, I wanted to check with you if you would like to be reminded of any of the components of the consent form?

Introduction for participants who want to fill our survey over the phone:
Before beginning the interview, I will start by going through each component of the consent form to explain what this study is aiming to do, any potential benefits and risks. If you do not wish to participate after hearing the components of the consent form, we do not need to move forward with the interview. If you still want to participate, I will begin by asking you a few simple demographic questions. You are not obligated to answer any questions where you may feel uncomfortable in doing so, and we can just pass that question and move onto the next. Do you have any questions before we begin?

Consent Script:
Note: This consent script will be used if: 1) if a participant is unable to access the online questionnaire or 2) the participant wants to be reminded of components of the consent form they previously filled out.

Introduction:
Hello, my name is Emily Giroux and I am a 2nd year Master's student at the University of British Columbia Okanagan. Thank you for your interest in participating in our study which looks at ways to enhance the lives of individuals aging with a spinal cord injury. For this project, I am working under the supervision of Dr. Heather Gainforth in UBC Okanagan's School of Health and Exercise Sciences.

Purpose: The purpose of this study is to develop a first-hand understanding of experiences of participation in individuals aging with a spinal cord injury (SCI). This research study aims to work with SCI Alberta, SCI BC and SCI Ontario to develop recommendations for tools, resources or programs designed to enhance participation in individuals aging with a SCI. You are being invited to take part in this research because you are a person who is currently aging with a SCI (i.e. minimum 45 years of age, minimum of 10 years post-injury)

Study Procedures: For this study, you will have either previously completed an online contact information survey or you will complete the online contact information survey over the phone with a member of the research team. At the time of the interview, you will be asked to consent to the interview being audio-recorded by a member of the research team. For the duration of the

interview, you will be asked a series of questions that will relate to your personal experiences while aging with a SCI, any barriers or facilitators to participation that you may have experienced while aging with a SCI, and any components you would like to see in a tool, resource or program designed to support participation while aging with a SCI. In total, the interview should take approximately 60-90 minutes to complete.

Benefits:
Your participation in this study will allow for a better understanding of how we can develop tools, resources or programs designed to enhance participation in individuals aging with a SCI.

Potential Risks:
There are no known physical, psychological, economic, or social risks associated with this study. You should not feel obliged to answer any material or participate in anything that you find objectionable or that makes you feel uncomfortable. You may also withdraw from the study at any time by contacting Dr. Gainforth by phone or by email.

Confidentiality:
This online questionnaire is administered by the UBC-hosted version of FluidSurveys. All data will be stored and backed up in Canada. All information provided will be kept strictly confidential. Electronic survey data will be stored in password-protected files on a password-protected computer in Dr. Gainforth's Lab at UBC Okanagan. All paper records will be stored in a locked cabinet in Dr. Gainforth's Lab at UBC Okanagan. The data from this study may be published in professional journals or presented at scientific conferences, but any such presentations will be of general findings only and will never breach your confidentiality.

Compensation: You will receive a $20 gift card to one of the following retailers (i.e. Starbucks, Tim Hortons, Cineplex, Bath and Body Works, Best Buy) for participating in this study. You will be able to indicate how you would like to receive your gift card (i.e. by mail or by e-mail) in the survey that will be filled out before the interview.

Contact for information about the study: If you have any inquiries or would like further information in regards to this study, you may contact Dr. Heather Gainforth at (250) 807–9352 or toll free at 866-835-8979, mailbox 91042. If you require information and reside outside of British Columbia, please feel free to email at heather.gainforth@ubc.ca or abc.lab@ubc.ca.

Contact for concerns about the rights of research subjects: If you have any concerns about your treatment or rights as a research participant, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598 or if long distance e-mail to RSIL@ors.ubc.ca.

Consent: Your participation in this study is completely voluntary and you are free to not answer any of the questions. You may withdraw from this study at any time without any consequences by merely exiting the survey by closing your browser. If you prefer, you can email Dr. Gainforth to withdraw and have your data removed from the study.

Before moving forward,
1) Do you have any further questions or would like any additional details of the study?
2) Do you consent to participate knowing you may withdraw at any point with no consequences?

Interview Script:

Part A: Consent & Participant ID Code

Please confirm that you consent to having this conversation recorded.

In order to maintain confidentiality, we will be creating a unique ID code for each participant.

1) What are the first three letters of your mother's maiden name?
2) What are the two digits of your day of birth?
3) What are the last two digits of your telephone number?

Part B: Background & Aging Perspective

Introductory Questions	Can you tell me about yourself? Could you tell me about some of your favourite activities or hobbies that you like to do? Please describe a typical day in your life.
Broad Questions	Which aspects of your life are most important to you as you age? And why? How have your life priorities changed as you have been aging? Which tasks/everyday activities are most important to you as you age? And why?
Definition Question	In your opinion, how would you define "ideal or "successful" aging while growing older with a spinal cord injury? **Probe:** Do you feel your definition of "ideal"/ "successful" aging is achievable? Why or why not?

Part C: Barriers to Ideal/Successful Aging

Broad Question	**Barrier:** What currently stops you or would stop you from being able to achieve your idea of "ideal" or "successful" aging? Of the tasks, roles, and everyday activities identified earlier that are most important to you as you age, what factors make it difficult or make you unable to do these tasks/roles/everyday activities? **Facilitator:** What currently helps you or would help you from being able to achieve your idea of "ideal" or "successful" aging? Of the tasks, roles and everyday activities identified earlier that are most important to you as you age, what factors make it easier to do these tasks/roles/everyday activities?
Physical Capability	**Barrier:** In terms of your physical function and health, what currently stops you from achieving your idea of "ideal" or "successful" aging? What stops you from engaging in (insert identified behaviour) in terms of your physical function and health? (Note: Repeat question for each task identified during broad questioning) **Facilitator:** In terms of your physical function and health, what currently helps you achieve your idea of "ideal" or "successful" aging? What helps you engage in (insert identified behaviour) in terms of your physical function and health?

Psychological Capability	What do you currently know about ways to successfully age with a spinal cord injury? What do you already know about continuing to/not being able (insert identified behaviour) with increasing age? Do you feel you have the necessary knowledge and information in order to successfully age? Do you feel that you have the necessary knowledge and information to continue (insert identified behaviour) (Note: Repeat question for each identified behaviour) o **Yes:** How do you know/are aware of the information/knowledge required to continue/be able to (insert identified behaviour) o **No:** How do you think you could you become more aware of the knowledge/information?
Physical Opportunity	Do you feel that the environments you live in/ work in/spend time in regularly help you or stop you from achieving your idea of "ideal"/ "successful" aging? Why? o **Probe:** How does the environment help/stop you? o **Probe:** If they stop you, how can the environment be changed? Do you feel that the environment you live in/work in/spend time in regularly helps you or stops you from (insert identified behaviour)? o **Probe:** How does the environment help/stop you? o **Probe:** If the environment stops you, how could the environment be changed?
Social Opportunity	Do you feel that the people you spend your time with on a daily basis help you or stop you from achieving your idea of "ideal"/ "successful" aging? Why?

	○ **Probe:** What do they do that helps/stops you? ○ **Probe:** If they stop you, what could they do differently? Do you feel that the people you spend your time with on a daily basis help you or stop you from engaging in (insert identified behaviour)? ○ **Probe:** What do they do that helps/stops you? ○ **Probe:** If they stop you, what could they do differently? Do you know of any other individuals with a SCI who are achieving your idea of "ideal"/ "successful" aging? ○ **Probe:** If so, what are they doing (e.g. daily activities, groups, programs) to achieve this idea. Do you know of any other individuals with a SCI who are able to successfully engage in (insert identified behaviour) (Note: Only ask this question for behaviours where barriers are identified) ○ **Probe:** If so, what are they doing to be able to engage in this behaviour?
Reflective Motivation	Do you see value in continuing to participate in life situations as you age? Why? Are you confident in your ability to participate in life situations as you age? Why? Do you have a plan in place to ensure you can ensure you continue to participate as you age? ○ **Probe:** Yes – what does this plan entail? ○ **Probe:** No – if you were to develop a plan, what would you think this plan would need to contain? ○
Automatic Motivation	How do your emotion influence how you participate in life situations?

	○ **Probe:** Positive feeling – What makes you feel positively about aging ○ **Probe:** Negative feeling – What makes you feel negatively about aging Are you afraid or worried participating in life situations as you grow older with a spinal cord injury? If so, why or why not? ○ Do you have resources available to deal with this fear or worry? ○ **Yes:** What are these resources? ○ **No:** Are you aware of using peer support to deal with this fear/worry? Do you receive any rewards or incentives that influence how you participate in life situations? Do these motivate you in any way?

Part D: Tool/Resource/Program Design & Implementation

Broad Question:	The aim of my thesis project is to develop recommendations for a tool, resource or program that can be used to support individuals as they age with a spinal cord injury. The tool, resource or program will focus on maintaining your ability to participate. For example, it may include your ability to continue to have strong relationships with others and to fulfill your daily roles and responsibilities. In order to design a tool, resource or program that aims to support your ability to successfully age, what content would you like to see in this tool, resource or program? Who would you like to deliver these tools, resources or programs (e.g. SCI organization, medical professional, peer)?

	How would like to have the information presented (e.g. online, newsletter, face-to-face)?
Conclusions	Is there anything else you would like me to know? Do you have any further questions about the study you would like me to answer? Thank you so much for your time today. You will receive $20 in the form of a gift card to the retailer of your choice from the 5 options for completing the interview today. Your compensation will be received in the format requested when completing the initial contact information survey.

Appendix F: TDF Coding Manual

TDF Coding Manual: Domains and Corresponding Definitions and Constructs

Table 4 TDF Coding Manual: Domains and Corresponding Definitions and Constructs

TDF Domain	Definition	Constructs
Behavioural Regulation	Anything aimed at managing or changing objectively observed or measured actions	Self-monitoring Breaking habit Action planning
Belief about Capabilities	Acceptance of the truth, reality or validity about an ability, talent or facility that a person can put to constructive use	Self-confidence Perceived competence Self-efficacy Perceived behavioural control Beliefs Self-esteem Empowerment Professional confidence
Belief about Consequences	Acceptance of the truth, reality or validity about outcomes of a behaviour in a given situation	Beliefs Outcome expectancies Characteristics of outcome expectancies Anticipated regret Consequents

TDF Domain	Definition	Constructs
Emotion	A complex reaction pattern involving experiential, behavioural and physiological elements, by which the individual attempts to deal with a personally significant matter or event	Fear Anxiety Affect Stress Depression Positive/negative affect Burn-out
Environmental Context and Resources	Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence and adaptive behaviour	Environmental stressors Resources/material resources Organizational culture/climate Salient events/critical incidents Person x environment interaction Barriers and facilitators
Goals	Mental representations of outcomes or end states that an individual wants to achieve	Goals (distal/proximal) Goal priority Goal/target setting Goals (autonomous/controlled) Action planning Implementation intention

TDF Domain	Definition	Constructs
Intentions	A conscious decision to perform a behaviour or a resolve to act in a certain way	Stability of intentions Stages of change model Transtheoretical model and stages of change
Knowledge	An awareness of the existence of something	Knowledge (including knowledge of condition/scientific rationale) Procedural knowledge Knowledge of task environment
Memory, Attention and Decision Processes	The ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives	Memory Attention Attention control Decision making' Cognitive overload/tiredness
Optimism	The confidence that things will happen for the best or that desired goals will be attained	Optimism Pessimism Unrealistic optimism Identity
Reinforcement	Increasing the probability of a response by arranging a dependent relationship or contingency, between the response and a given stimulus	Rewards (proximal/distal, valued/not valued, probable/improbable)

TDF Domain	Definition	Constructs
		Incentives Punishment Consequents Reinforcement Contingencies Sanctions
Skills	An ability or proficiency acquired through practice	Skills Skills development Competence Ability Interpersonal skills Practice Skills assessment
Social Influences	Those interpersonal processes that can cause individuals to change their thoughts, feelings or behaviour	Social pressure Social norms Group conformity Social comparisons Group norms Social support Power Intergroup conflict Alienation

TDF Domain	Definition	Constructs
		Group identity Modelling
Social/Professional Role and Identity	A coherent set of behaviours and displayed personal qualities of an individual in a social or work setting	Professional identity Professional role Social identity Identity Professional boundaries Professional confidence Group identity Leadership Organizational commitment

Note: TDF Coding Framework is based on domains, definitions and constructs provided in Cane, O'Connor & Michie (2012). Validation of the theoretical domains framework for use in behaviour change and implementation research

Appendix G: Intervention Function Coding Manual

Table 5

Intervention Function Coding Manual: Functions and Corresponding Definitions

Intervention Function	Definition
Coercion	Creating an expectation of punishment or cost
Education	Increasing knowledge or understanding
Enablement	Increasing means/reducing barriers to increase capability (beyond education and training) or opportunity (beyond environmental restructuring)
Environmental Restructuring	Changing the physical or social context
Incentivization	Creating an expectation of reward
Modelling	Providing an example for people to aspire or imitate
Persuasion	Using communication to induce positive or negative feelings or stimulate action
Restriction	Using rules to reduce the opportunity to engage in the target behaviour (or to increase the target behaviour by reducing the opportunity to engage in competing behaviours)
Training	Imparting skills

Note: Intervention Coding Manual is based on Michie, Atkins & West (2014). The Behaviour Change Wheel: A Guide to Designing Interventions

Appendix H: MoDtv0 Coding Manual

Table 6

MoDtv0 Coding Manual: Human Categories and Corresponding Definitions

Mode of Delivery Category	Definition
Human (Top-Level) *i. Face-to-face, distance*	Delivery through human contact in which the participant sees and/or hears a person in real-time
Face-to-Face (Sub-Level 1)	Delivery through human contact in which the participant meets a person in real-time, face to face
Distance (Sub-Level 1) *ii. Audio Call, Video Call, Text Message, Instant Message*	Delivery through human contact in which the participant has contact with a person at a distance
Audio Call (Sub-Level 2)	Delivery through a telephone call involving audio/voice only
Video Call (Sub-Level 2)	Delivery through a call involving both audio and picture
Text Message (Sub-Level 2)	Delivery through a written message sent via SMS from a person (i.e. as opposed to automated SMS)
Instant Message (Sub-Level 2)	Delivery through a written message sent via an instant messaging system sent from a person (i.e. online chat function)

Note: MoDtv0 Coding Framework is based on Carey, Evans, Horan, Johnston, West & Michie (2016) Mode of Delivery of Behaviour Change Interventions Taxonomy version 0 (MoDtv0)

Table 7

MoDtv0 Coding Manual: Printed Categories and Corresponding Definitions

Mode of Delivery Category	Definition
Printed Material (Top-Level) *i. Letter, Poster, Leaflet, Labelling, Public Notice*	Delivery through information produced on paper; can be hand-delivered or posted to the participant; materials can include diagrams, pictures and text
Letter (Sub-Level 1)	Delivery through a written communication, sent in letter format by post or delivered in person
Poster (Sub-Level 1)	Delivery through a printed picture, containing text and/or images, usually displayed on a notice board or wall
Leaflet (Sub-Level 1)	Delivery through a small-sized booklet
Labelling (Sub-Level 1)	Delivery through a product label; usually relating to the object to which it is attached
Public Notice (Sub-level 1)	Delivery through a notice, sign or billboard in a public place

Note: MoDtv0 Coding Framework is based on Carey, Evans, Horan, Johnston, West & Michie (2016) Mode of Delivery of Behaviour Change Interventions Taxonomy version 0 (MoDtv0)

Table 8

MoDtv0 Coding Manual: Digital Categories and Corresponding Definitions

MOD Category	Definition
Digital (Top-Level) *i. Phone, Computer/Television, Wearable, Environmental Sensor*	Delivery through a form of digital technology, including computer, smartphone, tablets, television and wearable or environmental devices
Phone (Sub-Level 1) *ii. E-mail, Website, Video Game, Podcast, Social Media, App, Automated Text Message*	Delivery through a hand-held device that delivers information through electronic digital signals (i.e. a "smart" phone)
E-mail (Sub-Level 2)	Delivery through a message sent via electronic messenger to a specific e-mail address
Website (Sub-Level 2)	Delivery through a set of pages of information published on the internet
Video Game (Sub-Level 2)	Delivery through a game in which the player controls moving pictures on a screen by pressing buttons
Podcast (Sub-Level 2)	Delivery through a radio program, stored in digital format and downloaded from the internet
Social Media (Sub-Level 2)	Delivery through a website that allows people to communicate and share information

MOD Category	Definition
App. (Sub-Level 2)	Delivery through a purpose-built stand-alone piece of software designed for a particular purpose
Automated Text Message (Sub-Level 2)	Delivery through an automated SMS (i.e. sent from a computerized system)
Computer/Television (Sub-Level 1) *ii. E-mail, Website, Video Game, Podcast, DVD, Social Media, Virtual Reality*	Delivery through a computing device (desktop/laptop/tablet) or television set
E-mail (Sub-Level 2)	Delivery through a message sent via electronic messenger to a specific e-mail address
Website (Sub-Level 2)	Delivery through a set of pages of information published on the internet
Video Game (Sub-Level 2)	Delivery through a game in which the player controls moving pictures on a screen by pressing buttons
Podcast (Sub-Level 2)	Delivery through a radio program, stored in digital format and downloaded from the internet
DVD (Sub-Level 2)	Delivery through a digital video disc used for storing and playing information
Social Media (Sub-Level 2)	Delivery through a website that allows people to communicate and share information
Virtual Reality (Sub-Level 2)	Delivery through an immersive and interactive 3D experience involving a set of images/sounds produced by a computer,

MOD Category	Definition
	which represent a place/situation in which a person can take part
Wearable (Sub-Level 1) *ii. Clothing, Accessory*	Delivery through a digital technology device worn on the body (e.g. pedometer)
Clothing (Sub-Level 2)	Delivery through a digital device embedded into clothing
Accessory (Sub-Level 2) *iii. Virtual Reality*	Delivery through a digital device worn on the person; includes watch, clip-on, glasses, smart in-ear devices
Virtual Reality (Sub-Level 3)	Delivery through an immersive and interactive 3D experience involving a set of images/sounds produced by a computer, which represent a place/situation in which a person can take part
Environmental Sensor (Sub-Level 1)	Delivery through a digital device that detects and/or responds to events in, changes to, or input from the physical environment

Note: MoDtv0 Coding Framework is based on Carey, Evans, Horan, Johnston, West & Michie (2016) Mode of Delivery of Behaviour Change Interventions Taxonomy version 0 (MoDtv0)

Table 9

Somatic Modes of Delivery

MOD Category	Definition
Somatic (Top-Level) *i. Patch, Pill, Inhaler, IV/Injection, Liquid, Subcutaneous*	Delivery through a device designed to act within the body
Patch (Sub-Level 1)	Delivery through material attached to the skin; usually serves a chemical and/or medicinal purpose
Pill (Sub-Level 1)	Delivery through a small round mass of solid medicine, swallowed whole
Inhaler (Sub-Level 1)	Delivery through a device producing vapor to medicate and/or ease breathing via inhalation
IV/Injection (Sub-Level 1)	Delivery through a fluid substance
Liquid (Sub-Level 1)	Delivery through a fluid substance
Subcutaneous (Sub-Level 1)	Delivery through a device situated under the skin

Note: MoDtv0 Coding Framework is based on Carey, Evans, Horan, Johnston, West & Michie (2016) Mode of Delivery of Behaviour Change Interventions Taxonomy version 0 (MoDtv0)

Appendix I: Behaviour Change Matrices

Figure 4: TDF Domains Mapped Against COM-B Components (Source: Michie et al., 2011)

	Intervention functions								
	Education	Persuasion	Incentivisation	Coercion	Training	Restriction	Environmental restructuring	Modelling	Enablement
Physical capability					■				■
Psychological capability	■				■				■
Physical opportunity					■	■	■		■
Social opportunity						■	■	■	■
Automatic motivation		■	■	■	■		■	■	■
Reflective motivation	■	■	■	■					

Figure 5: COM-B Components Mapped Against Intervention Functions (Source: Michie et al., 2014)

	Policy categories						
	Communication / marketing	Guidelines	Fiscal measures	Regulation	Legislation	Environmental/ Social planning	Service provision
Education	■	■		■	■		■
Persuasion	■	■		■	■		■
Incentivisation	■	■	■	■	■		■
Coercion	■	■	■	■	■		■
Training		■	■	■	■		■
Restriction		■		■	■		
Environmental restructuring		■	■	■	■	■	
Modelling	■						■
Enablement		■	■	■	■	■	■

Figure 6: Intervention Functions Mapped Against Policy Categories (Source: Michie et al., 2014)

Appendix J: Quotes Representative of Each TDF Domain

Table 10

Representative Quotes of Each Identified TDF Domain

TDF Domain	Category	Quote
Behavioural Regulation	Hypothetical/Assumed Barriers	"*Individuals who have a pressure sore… the thing that makes it worse is that they fail to seek attention to it when it's a small thing and by the time they do seek attention for it, it's gotten to be a much bigger deal and a bigger problem as a pressure sore.*" **Behaviour:** Maintaining physical health
	Experienced Facilitators	*"[To do] something like pull the barbeque inside the trailer. For example, I could do it… figured out ways to hook [your own] tow rope on it to climb my ramp."* **Behaviour:** Participating in leisure and recreation activities
Beliefs about Capabilities	Experienced Barriers	*"I don't play basketball anymore because I can't keep up really... [the players] are way too fast, all these younger guys nowadays, and I probably should [play basketball] but I don't."* **Behaviour:** Participating in leisure and recreation activities
	Hypothetical/Assumed Barrier	*"If I can't transfer to sledge hockey, then I can't do it."* **Behaviour:** Participating in leisure and recreation activities
	Hypothetical/Assumed Facilitator	*"People that have a lower injury than me like say like have the use of their hands, would have a much easier time to take care of themselves than me because they move better right?* **Behaviour:** Everyday self-care (e.g. feeding, grooming, performing bowel care)

TDF Domain	Category	Quote
Belief about Consequences	Experienced Barrier	*"But yeah, for myself I can't travel as easily. Like to go to my mom's, it used to be like, you know you could transfer on a lower toilet, and you could either transfer on a shower bench or right into the bath tub or whatever. But nowadays, it's just so much harder like I can't even transfer onto her toilet. So, if I go there, I have to wear a leg bag and then do my bowel routine in the bedroom or something because I just can't get on their toilet. And I don't even have a shower for the few days I'm there, and I can only go for a few days because I can't have a shower."* **Behaviour:** Participating in holiday and travel activities
	Hypothetical/Assumed Barrier	*"Some stuff I've read on Facebook about people having issues with bladder, bowel or stuff like that makes you afraid to go anywhere because they don't want to be embarrassed out in the community."* **Behaviour:** Going out in the community (e.g. activities, accessing services)
	Experienced Facilitator	*"Massage helps keep my shoulders back and in place where they're supposed to be so that when I am doing [activities] my shoulders aren't forward. And you know where there's so much forward motion in a wheelchair and everything you do is forward; massage has helped quite a bit to help maintain my shoulder."* **Behaviour:** Maintaining physical health
	Hypothetical/Assumed Facilitator	*"I've just recently lost a lot of weight and I've noticed that I've probably lost a bit of muscle as well. I need to… yeah, I need to exercise more. I think that more exercise will definitely help that."* **Behaviour:** Maintaining physical health
Emotion	Experienced Barrier	*"Because I wasn't leaving the house prior to that, I was sick and when you're sick and you don't leave the house, you get more anxious. [Being anxious] causes depression and you become socially isolated."* **Behaviour:** Communicating with others, Maintaining mental well-being

TDF Domain	Category	Quote
	Hypothetical/Assumed Barrier	*"If you're staying home and doing nothing because you're afraid to go out. I mean for whatever reason, absolutely that's when the pressure sores start happening."* **Behaviour:** Going out in the community, maintaining physical health
Environmental Context and Resources	Experienced Barriers	*"The snow really affects me, or people like me, even more. Yeah, I was stuck in the house, didn't get to leave for 6 weeks or more and I felt like I was in prison and I got really… yeah got really depressed."* **Behaviour:** Going out in the community
	Hypothetical/Assumed Barriers	*"And if I was living on [a large, steep hill], I'd be like "No, I'm not pushing up a hill just stepping out my door.", being faced with a hill every time you step out your door, that's limiting to me, that's a barrier right."* **Behaviour:** Going out in the community
	Experienced Facilitators	*"Now that I do actually have some medication that helps with the pain relief that I can actually do some more exercises and be more social and stuff like that too."* **Behaviour:** Going out in the community, participating in leisure and recreation activities, communicating with others
	Hypothetical/Assumed Facilitators	*"But now when I'm at 50 and if this building is five years old, I'd kind of like a button on the door [to automatically open the door] because it would make my life a little easier."* **Behaviour:** Accessing services in the community
Goals	Hypothetical/Assumed Facilitator	*"So, it's important to put some money away for retirement and for whatever. You know so that you can… I think if you can you know do the things you want to do that make you happy, that also contributes to well-being and you're healthy and you know whether you're aging healthy or*

TDF Domain	Category	Quote
		whatever." **Behaviour:** Maintaining mental well-being, participating in activities
Intentions	Experienced Facilitator	*"I've never had a problem with my skin even though I'd be in the chair all day long. I was really good always about… well for one thing I was transferring in and out of my car a lot and I'm always pretty good about lifting myself. You know making sure that the circulation's flowing and that kind of thing. You know… moving around and that kind of thing, shifting my weight."* **Behaviour:** Maintaining physical health
Knowledge	Hypothetical/Assumed Barrier	*"Most people with disabilities don't work, because they aren't really exposed to it. They don't even think that's something they could or should be doing. It's just, it's a very strange limiting idea of themselves."* **Behaviour:** Carrying out paid productive activities
	Experienced Facilitator	*"I discovered that the skin breakdowns for me anyway… taking a high dose of Omega-3 was the solution to those skin breakdowns and since I was on a very high dose or Omega-3's… I've really not had any problems and that's been jeez, 7,8 years now."* **Behaviour:** Maintaining physical health
Memory, attention and decision processes	Hypothetical/Assumed Barrier	*"The thing that makes [a pressure sore]* worse is that *[people] fail to seek attention to it when it's a small thing and by the time they do seek attention for it, it's gotten to be a much bigger deal and a bigger problem as a pressure sore."* **Behaviour:** Maintaining physical health
Skills (Physical)	Experienced Barriers	*"I'm finding that I don't drive as much anymore because getting in and out of the car is wrecking my shoulders and wrecking my hands and wrists"* **Behaviour:** Moving using transportation

TDF Domain	Category	Quote
	Hypothetical/Assumed Barrier	*"I mean personally for me it's fat, it's a health issue for your heart and your body and all that kind of stuff. Your chair needs to be bigger, so that much narrower of a door you cannot fit through; transfers into vehicles, transfers into bed, transfers into anything are more physically difficult for you."* **Behaviour:** Moving in your home and nearby surroundings
	Experienced Facilitator	*"Now I can't gain weight, so I like to sort of gain a little bit of weight for reserve in case I get sick. Um and that [weight] could you know, helps me to be able to get around and move around and be independent."* **Behaviour:** Moving in your home and nearby surroundings, going out in the community
Skills (Ability)	Experienced Barriers	*"And if you can't go to the bathroom, to be quite honest there's things that a lot of able-bodied people don't think about. If you can't go to the bathroom by yourself and you need help with that, then how many hours can you go out on the ski hill too. I mean there's all kinds of things that are preventing me from doing what I used to."* **Behaviour:** Participating in leisure and recreation activities
	Hypothetical/Assumed Facilitator	*"People that have a lower injury than me like say like have the use of their hands, would have a much easier time to take care of themselves than me because they move better right?* **Behaviour:** Everyday self-care (e.g. feeding, grooming, performing bowel care)
Social Influences	Experienced Barriers	*"I go out as much as possible and uh, spend time eating out and trying to socialize on the outside as much as possible. But [going out] is limited because most people are employed so."* **Behaviour:** Communicating with others, going out in the community

TDF Domain	Category	Quote
	Hypothetical/Assumed Barrier	*"It's important to make sure that physicians don't give out too many disabled parking plaques or permits because then the one's that really need those spots can't get to them"* **Behaviour:** Going out in the community (e.g. accessing services, activities)
	Experienced Facilitator	*"Like perfect example the other day, wheeling up the ramp, go to the same restaurant we always go to or whatever and I noticed my friend just put her hand on my back push handle and just gave me a little shove. Nothing really had to be said and I didn't fight it off and she didn't even mention it."* **Behaviour:** Going out in the community
Social/Professional Role and Identity	Experienced Barrier	*"Where I live in this apartment building, there's an office out there and an office manager and a maintenance schedule and then I'll go out there, talk to them for a little while because I used to be active on the board there, but I got voted off this year so I'm not so active now."* **Behaviour:** Carrying out unpaid productive activities, participating in activities and organizations
	Experienced Facilitator	*"I'm actually a real home body, so making commitments to things helps me get out and be active. The volunteer work obviously helps me to be able to get out, keeps me connected to the community, helps me know what's going on because I, you know like to be involved in things. So I like to know what's going on and what's happening and being able to help you know, shape the future of athletics or wheelchair sport so you know those things are important to me.* **Behaviour:** Carrying out unpaid productive activities, participating in activities and organizations
TDF Not Applicable (Nature of the Behaviour)	Experienced Facilitator	*"So now whatever activity I'm going to do, and I like to do lots – you know I like to participate in any activities that I can, but only on… not at a*

TDF Domain	Category	Quote
		competitive level. Only for relaxation or enjoyment or that just… sense of belonging so that you know I'm not, so that I know that I can still participate in community, participate in life and still have activities that I can share with my friends, with my family." **Behaviour:** Maintaining relationships with others, participating in activities and organizations

Note: Underlined segments of each quote are representative of the identified TDF domain