

RESEARCH ARTICLE

Using the theoretical domains framework to guide the development of a self-management program for individuals with spinal cord injury: Results from a national stakeholder advisory group

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Objective: To determine the implementation considerations for a targeted self-management program for individuals with spinal cord injury (SCI) from the perspective of a national stakeholder advisory group using the Theoretical Domains Framework (TDF) as a guide.

Design: Qualitative descriptive approach.

Setting: Two focus groups held at the 6th National Spinal Cord Injury Conference (October 2–4th, 2014) in Toronto, Ontario, Canada.

Participants: A total of 25 stakeholders from across Canada participated in focus groups or “brainstorming sessions”. The stakeholders included 5 clinicians, 14 researchers, 3 policy makers, and 3 individuals with SCI.

Interventions: Not applicable.

Outcome Measures: Not applicable.

Results: All 14 theoretical domains were identified in the brainstorming sessions. No new themes or domains were identified. The need to consider the theoretical domains of Knowledge, Skills, Reinforcement, Intentions, Goals (e.g. the readiness of the individual with SCI), Environmental Context and Resources (e.g. considerations for governance and ownership of the program and a business model for sustainability), as well as Social Influences (e.g. issues of privacy and security in the context of on-line delivery) was identified.

Conclusions: The current study provides complementary results to our previous series of studies on the implementation considerations for the development of a targeted self-management program for individuals with SCI by emphasizing the health care professional/health policy perspective. It is anticipated that such a program could not only reduce secondary complications and subsequent inappropriate health care use but it may also improve the quality of life for individuals with SCI and their caregivers.

Keywords: Theoretical domains framework, Self-management, Spinal cord injury, Qualitative descriptive

Introduction

High utilization rates of health care services in individuals with spinal cord injury (SCI)^{1–5} suggest that care needs in the community are not being met for this population. Given the reduced lengths of inpatient rehabilitation stay, persons with SCI often require outpatient

community services to manage secondary conditions that have not stabilized at the time of index discharge.⁶ Families and others comprising informal support networks also have less time to adjust.⁴ There is a need to bridge the gap between hospital and home and to develop and implement strategies that increase patients’ self-care skills and involvement in and control of their care.⁷ One strategy is to develop a targeted self-management program for individuals with SCI.

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Self-management is commonly described as “... the individual’s ability to manage the symptoms, treatment, physical, and psychosocial consequences and lifestyle changes inherent in living with a chronic condition. Efficacious self-management encompasses the ability to monitor one’s condition and to affect the cognitive, behavioral, and emotional responses necessary to maintain a satisfactory quality of life”.⁸ Self-management has been reported as enabling individuals to minimize pain, share in decision making about treatment, gain a sense of control over their lives,^{9,10} reduce the frequency of visits to physicians, and enjoy a better quality of life.^{9,11}

A study on the experiences of individuals with neurological conditions, including stroke, multiple sclerosis, and SCI, who participated in the Stanford Chronic Disease Self-Management Program (CDSMP), demonstrated that participants with SCI reported the least satisfaction with the CDSMP. Individuals with SCI as well as some of the group leaders of the CDSMP in this study suggested the development of a SCI-specific program (e.g. individuals with SCI needed information specific to and modules adapted for being in a wheelchair/reduced mobility).¹² In addition, this study found that for situations where attendant care is important (as is the case in individuals with SCI), a different approach may be needed to teach self-management skills (i.e. being a good director of care, instead of a person who actually manages care independently).¹² Similarly, our research team investigated implementation considerations for a targeted self-management program for individuals with traumatic SCI from the perspective of individuals with SCI, their family members/caregivers, and managers from acute care/trauma and rehabilitation centres (n=26).¹³⁻¹⁶ Among our findings, we identified content areas for a proposed self-management program in SCI including exercise, nutrition, pain management, and information/education on aging with SCI as well a desire for program delivery via the internet. We also determined that the program should form groups of individuals with a similar level of injury and age. The need for both health care professional and peer facilitation was highlighted.¹⁴ In order to build on these findings, with the ultimate aim of designing and implementing a tailored self-management program for individuals with SCI, we adopted the Theoretical Domains Framework (TDF).^{17,18}

The developers of the TDF identified 33 theories and 128 key theoretical constructs related to behaviour change and amalgamated them into a single framework to evaluate implementation and other behavioural challenges and inform intervention development. A later paper tested the validity of the framework.¹⁸

The developers used a six stage consensus approach including 1) ascertaining theories and theoretical constructs germane to behaviour change, where a theoretical construct is operationalized as ‘a concept specially devised to be part of a theory’; 2) simplifying these resulting constructs into overarching theoretical domains, where a theoretical domain is operationalized as ‘a group of related theoretical constructs’; 3) assessing the importance of the theoretical domains; 4) performing an interdisciplinary evaluation and synthesis of the domains and constructs; 5) confirming the domain list; and, 6) pilot testing interview questions relevant to the constructs and domains. This approach and the later paper on testing the validity of the framework resulted in 14 theoretical domains and example questions for each to use in interviews or focus groups to provide a comprehensive theoretical evaluation of implementation challenges or list of considerations for developing an intervention, as was the case in the current study. These theoretical domains include: Knowledge, Skills, Social/Professional Role and Identity (i.e. self-standards); Beliefs about Capabilities (i.e. self-efficacy); Optimism; Beliefs about Consequences (i.e. anticipated outcome/attitudes); Reinforcement, Intentions; Goals; Memory, Attention and Decision Processes; Environmental Context and Resources (i.e. environmental constraints); Social Influences (i.e. norms); Emotion, and Behavioural Regulation.¹⁸ The TDF informed the questions used in the focus group guide as well as the coding framework/themes developed. Thus, this study aims to determine the implementation considerations for a targeted self-management program for individuals with SCI from the perspective of a national stakeholder advisory group using the TDF as a guide.^{17,18} The TDF was selected as its domains align well with our aim to determine the implementation considerations, including the barriers and facilitators, of a self-management program for individuals with SCI.

Methods

Design/approach

The current study took a qualitative descriptive approach using focus groups. This approach was used as there is a paucity of research on self-management in individuals with SCI and the qualitative descriptive approach is well-accepted for researching topics about which little is known so as to yield answers relevant to policy makers and health care practitioners.^{19,20} We have used this approach previously in our other, related studies.^{13,16} Moreover, in qualitative research, especially, it is important to understand/disclose the

underlying paradigmatic assumptions. Understanding and disclosing these assumptions can ensure that appropriate criteria are applied to appraise the research.²¹ The current research was underpinned by a pragmatic approach. Pragmatic research is motivated by anticipated outcomes.²² The common ground when adopting a pragmatic approach is the emphasis on practical usefulness and consequences of ideas and statements, as was the case in the current study.²³

Recruitment and data collection

Individuals who planned to attend the 6th National Spinal Cord Injury Conference including the pre-course (October 2–4th, 2014) in Toronto, Ontario, Canada as well as local stakeholders (e.g. SCI researchers, policy makers) were invited to participate in the focus groups or “brainstorming sessions.” Participants were divided randomly into two groups and each group took part in two brainstorming sessions lasting approximately 45 minutes. After each session, there was a representative from each group who summarized the discussion for the larger group. This summary of the discussion lasted approximately 10 minutes (i.e. 5 minutes for each group). Two of the study authors (SEPM, SBJ) led the discussions for each group. At the end of the brainstorming sessions and discussion periods, the larger group (i.e. all participants) participated in a discussion including implementation considerations (i.e. next steps/ideas for moving forward). Discussions were recorded by typed-note taking during the sessions by one member of the research team (SA) using password-protected laptops.

The semi-structured interview guide was devised using the TDF as a guide and included the following questions: 1a) In your opinion, what would be important to include in a self-management program for persons with SCI?; 1b) For each of the elements you identified, should the focus be: education, skills development, behaviour change, or a combination? What would be the modes of delivery (how would you provide this – online, binder, etc.)? Who is the program’s audience (self, peer, health care professional, advocacy groups, etc.) or recipients (individuals with traumatic/non-traumatic SCI, time since injury as a factor, level of injury as a factor, caregivers, etc.)?; 2) What are barriers and enablers to operationalizing what we discussed in Questions 1a and 1b? The following areas were asked as probes: Self-efficacy/past experience? Resources? Attitudes/beliefs/consequences (outcome expectancy)? Knowledge? Existing skill level? Motivation (readiness, goals, incentives)? Role/identity (health care professional, client)? Accessibility? Organizational commitment/champions/

funders/administrators? Social support/pressure/competing demands? Emotion (depression, burn-out, stress, cognitive overload)? 3) How should these barriers and enablers be addressed (i.e. how would you overcome/minimize the barriers and enhance the enablers?)

Data analysis

A deductive thematic analysis as described by Braun and Clark²⁷ was performed on the data to explore the implementation considerations for a targeted self-management program for individuals with SCI from the perspective of national stakeholder advisory group. We have used this approach to data analysis in prior, related studies.^{13,16} Following verification of the accuracy of the typed notes, three members of the research team (SEPM, SA, SBJ) read the documents to become familiar with the data. The notes were coded manually by all three researchers (SEPM, SA, SBJ) giving full attention to all data. Following this, the codes were clustered into groups that shared similar meanings and mapped onto each of the theoretical domains. New themes were also considered. Together, the researchers explored various thematic maps until consensus was reached and theme labels were agreed upon.

Trustworthiness of the data and interpretations

Trustworthiness in qualitative research corresponds to validity in quantitative research and has been used in similar studies.^{21,24} Writing decision trails in which the methods of data collection and analysis are documented is important so that another researcher can check the trustworthiness of the entire process of study.²⁵ Guba and Lincoln outlined four criteria for checking trustworthiness and decision trails in qualitative research: credibility, transferability, dependability, and confirmability. Credibility is demonstrated through a) member check; b) peer debriefing; c) prolonged involvement; d) persistent observation; and e) triangulation.²⁶ In the current study, we did not conduct member checking. However, an expert in qualitative research ensured that the data and interpretations were clear and audited the study process. Our study group was extremely familiar with most of the participants through professional contacts prior to this study. Moreover, multiple methods for recruiting participants assured the variations in data that are the rationale for triangulation.

Results

A total of 25 stakeholders from across Canada participated in the focus groups or “brainstorming sessions.” The stakeholders included 5 clinicians, 14 researchers, 3 policy makers, and 3 individuals with SCI. All 14

theoretical domains were identified in the brainstorming sessions. No new themes or domains were identified. A summary of the results is presented in [Table 1](#).

For the Knowledge domain, participants highlighted that information included in a self-management program must be accurate and well timed (i.e. the readiness of the individual with SCI must be considered). Furthermore, participants discussed that the information presented in the self-management program must consider the (health) literacy of the program participants (i.e. the presented information should be simple to understand and avoid jargon). For the Skills domain, participants discussed the importance of certification/training for those delivering the program (e.g. peer mentors, caregivers, health care professionals, etc.). Participants also highlighted the need to consider/account for various characteristics of the program participants (e.g. different skill levels and the potential for a wide age range). In terms of the Social/Professional Role and Identity domain, participants discussed that the self-management program would need to link with primary care so that they are aware of the program and could make referrals to the program. For the Beliefs about Capabilities domain, the importance of peers in the SCI community was discussed including the importance of having peers to encourage the adoption of the program. Participants also discussed the importance of social media for promotion of the program, including linking individuals with SCI with peer mentors. Participants also mentioned that many individuals with SCI may not believe that they can self-manage because they are not familiar with the term self-management and what it entails (and thus it may be inappropriate to label a future program as a self-management program). In terms of the Beliefs about Consequences domain, participants discussed the importance of creating a program where the intended outcomes of the program match the expectations of the individuals with SCI (i.e. the program should be derived from input from individuals with SCI). Participants discussed many ideas related to the Reinforcement, Intentions, and Goals domains, including the need to consider the program participant's stage of injury (i.e. newly injured or many years since injury), the potential need to include tools to assess readiness for self-management as part of program participation, and the need for the program to account for each individual's specific needs (including customization/tailoring and priority setting for each individual). For the Memory, Attention and Decision Processes domain, participants discussed practical aspects of the self-management program including the need for accessible

information (i.e. "two-clicks" to access the information) and that the program should fit into the schedule of the individual with SCI. For the Environmental Context and Resources domain, participants discussed an overarching theme of the need to leverage existing resources including existing peer support networks/program. The issue of governance and ownership of the program was also discussed. For the Social Influences domain, participants discussed privacy and security measures (especially in the context of on-line delivery) and the fact that participants in such programs can deliver misinformation. The influence of spouses and caregivers was discussed including the fact that spouses and caregivers may want and need their own self-management support program (and that this need could occur before the individual with SCI is ready to participate in his or her own self-management program). For the domain of Optimism/Emotion, participants discussed that many program participants may experience embarrassment and stigma, especially when discussing difficult topics such as bladder management. It was indicated that embarrassment may be especially relevant for youth. The need to include content on depression was also raised. For the domain of Behavioural Regulation, participants indicated that the program should be based on adult learning principles; some of the suggested content areas related to behavioural regulation included stress management, secondary conditions and pain, coping, locus of control, social roles and relationships, problem solving, and developing action plans. Participants also emphasized that online tools should be leveraged in order to help individuals with SCI be involved in their self-management.

Discussion

The current study aimed to determine the considerations for implementing a targeted self-management program for individuals with SCI from the perspective of a national stakeholder advisory group using the TDF as a guide.^{17,18} Using a qualitative descriptive approach, all 14 domains of the TDF were identified in the brainstorming sessions/focus groups as important implementation considerations for a targeted self-management program in SCI. To the best of our knowledge, this is the first study to apply the TDF for the development of a self-management program.

We previously investigated the facilitators and barriers to self-management in traumatic SCI¹³ as well as the desired components of a self-management program and program delivery for individuals with traumatic SCI.¹⁴ The identified facilitators included physical

Table 1 Results of the Stakeholder Advisory Group Meeting Organized by the Theoretical Domains Framework

Theme/Theoretical Domain	Results
Knowledge	<ul style="list-style-type: none"> – Increase knowledge, skill, and confidence – The inpatient rehabilitation stay is typically very short and not much knowledge transferred, leaving individuals with SCI “unfinished” when they return to the community; there are new challenges, new learning opportunities. The self-management program must provide knowledge to meet these new challenges – The content must be evidence informed – Program participants must have knowledge on how to access the service and when to use it – The program must provide tools/knowledge on how to navigate crises – The information provided must be accurate/ well-timed – The [health] literacy of the program participants must be considered
Skills	<ul style="list-style-type: none"> – There should be education certification for those delivering the program – There is a need for training of program leaders, peer mentors, caregivers, health care professionals, etc. – There should be consideration for the inclusion of “assignments” to help consolidate skills (e.g. homework such as action plans that participants complete between sessions) – There is a need to account for different skill levels and age ranges
Social/Professional role and identity	<ul style="list-style-type: none"> – It is suggested that primary care is made aware of the program, linked to the program (e.g. the program has buy-in from the family physician so that he/she can make his/her patients aware of the program and promote it) – The adoption of programs are often driven/ facilitated by peers
Beliefs about capabilities	<ul style="list-style-type: none"> – There is a need to incorporate social media/ peer mentors for promotion of the program – Many individuals do not know that they can manage self-care (many individuals are not familiar with the term self-management) – It is important to note that SCI is not like another chronic disease; there is significant “baseline” divergence. Individuals with SCI must learn the “new normal”
Beliefs about consequences	<ul style="list-style-type: none"> – The knowledge and medical outcomes should match the outcome expectations of the individuals with SCI (i.e. the program should be derived from input from individuals with SCI) – One of the suggested outcomes should be the reduction of secondary complications (this serves funders and patients) – There is a need to consider the stage of injury (and relatedly, program leaders may need to assess individuals’ readiness for change using tools to assess readiness for self-management e.g. transtheoretical model, Patient Activation Measure – “Readiness” for information and self-management (i.e. timing for interventions) needs to be considered/is key – There are several phases of learning readiness; acute care is just the beginning – The levels of enthusiasm in individuals with SCI need to be considered – The program needs to be tailored to the patients’ needs (i.e. priority setting/per person; customizing to make them feel independent) – Measures of change in the patient should be collected (i.e. online data collection) – There is a divide between ongoing needs of individuals with SCI and crises
Memory, attention and decision processes	<ul style="list-style-type: none"> – There is a need for accessible information (i.e. information that is available in “2-clicks”) – The program must fit into the schedule of individuals with SCI

Continued

Table 1 Continued

Theme/Theoretical Domain	Results
Environmental context and resources	<ul style="list-style-type: none"> - There is a need to consider governance, ownership - National buy-in should be considered - There is a need to consider a business model for sustainability - A Central/backbone funding is needed - There is a need for a program that is affordable, accessible, available locally (e.g. provincial systems differ and there are different needs in urban and rural locations) - The SCI resources in the self-management program must be tailored to local context - There is a need to acknowledge that there are limited healthcare resources and capacity - Resources must be allocated to individuals with SCI (e.g. internet access, transportation to the program) - There is a need to acknowledge socio-economic barriers on the part of individuals with SCI - There might be issues with respect to computer, internet access - There is a need to create awareness of programs among health care professionals to endorse and market the programs - There is a need to incorporate an existing network of services - service "hub" (e.g. existing programs in rehabilitation centres) - There is a need to leverage peer supports - SCI organizations are a leading source of ongoing support; there is a need to integrate the proposed program with their existing tools with theirs (examples include SCI WIRE (chat channel, access peer responses), Strengthening Families Initiative (McGrath at Dalhousie), "Discovering the Power in me" SCI Nuggets (Rick Hansen Institute), SCI-U) - There is a need for resource consolidation: e.g. an "Info Atlas" - There is a need for a central/localized information repository - There is a need for triage-based systems (including tools to navigate crises), tools to assess symptoms and help determine needs/next steps - Strategies are needed to reach hard-to-reach clients - There is a need to include "booster sessions" in the community - There is a need to create adaptable modules that can be integrated with other programs - Different modalities (e.g. phone, online, smart devices, tablets, apps, face to face) to deliver boosters/training need to be considered - There needs to be a mechanism for routine updating - There is a need to consider developing program materials for different languages, cultures
Social influences	<ul style="list-style-type: none"> - Issues of privacy and security measures (what requires privacy/security) need to be considered, especially in the context of on-line program delivery - There is a need to prioritize input and feedback from individuals with SCI; the program needs to be informed and led by individuals with SCI (i.e. needs driven) - There is a need to consider convenience in delivery - what works for individuals with SCI? - There is a need to consider that support groups can also deliver misinformation (how should this be addressed/accounted for?) - The program needs to be community oriented - The spouse/caregiver may be ready for his/her own self-management support program and the individual with SCI needs to be open to that
Optimism, Emotion regulation	<ul style="list-style-type: none"> - There is a need to address stigma - The program should include content related to acceptance of disability (there are different frames of reference for what disability means) - There program should include content related to depression - There is a need to consider embarrassment especially for difficult topics like bladder management, particularly for youth - Self-management may be considered a "weird misnomer" and may need some rebranding (i.e. individuals with SCI may not know what self-management means, entails); - "Beyond Rehab" as an alternate name/brand for self-management could be considered
Behavioural regulation	<ul style="list-style-type: none"> - The program should be based on adult learning principles - Proposed content areas may include: stress management, secondary conditions and pain, coping, locus of control, social roles and relationships, problem solving, and developing action plans - Individuals must learn how to manage while waiting - Online tools that help to inform patients to be involved in their self-management must be prioritized

support from the caregiver, emotional support from the caregiver, peer support and feedback, importance of positive outlook and acceptance, and maintaining independence/control over care. The barriers to self-management included caregiver burnout, funding and funding policies, lack of accessibility, physical limitations and secondary complications, and difficulties achieving positive outlook or mood.¹³ As noted, we have previously identified content areas for a proposed self-management program in SCI including exercise, nutrition, pain management, and information/education on aging with SCI, as well as the need for an internet-based self-management program. We also determined that the program should have individuals of a similar level of injury and of a similar age. The need for both health care professional and peer facilitation was highlighted.¹⁴ Indeed, a recent randomized trial of a peer-led, telephone-based self-management intervention in adults with chronic SCI demonstrated a positive impact on self-management to prevent secondary conditions in adults with SCI.²⁸ Our previous research has emphasized the patient perspective (i.e. patient/individual level), while the current study emphasized a health care professional/policy maker perspective (i.e. health care system level). Consistent areas between the studies included the need to consider stage of injury and the individual's readiness for information and/or a self-management program, caregiver involvement, peer involvement, an internet-based mode of delivery, and the importance of certain content areas including dealing with depression, secondary complications, pain management, communication and relationship issues (family members, health care professionals), and problem solving. In the current study, and not surprisingly given the participants involved (i.e. health care professionals, policy makers, etc.), program delivery and environmental considerations were emphasized, including the need for training for those delivering the program, governance and ownership of the program, a business model for sustainability, and issues of privacy and security in the context of on-line delivery.

As previously mentioned, part of the contribution of this study is the use of the TDF to develop a targeted self-management program in SCI. This framework has been used previously by research teams to both assess implementation challenges and inform implementation interventions, as is the case in the current study. Use of the TDF also ensures that a wide range of facilitators and barriers are considered and that these domains can be linked to behaviour change techniques.^{17,18} For example, in Australia, the TDF has been used to

ascertain the barriers and facilitators to implementation of evidence-based guidelines for low back pain^{29,30} and inform theory-informed interventions. In Canada and the UK, examples include studies of the barriers and facilitators related to improving hand hygiene in hospitals^{31,32}; the assessment of theoretical domains pertinent to blood transfusion practice across different contexts including neonatal and adult intensive care units^{33,34}; and identifying challenges in using guidelines relating to schizophrenia.³⁵ In Denmark, the TDF has been used to understand behaviour in the implementation of tobacco use prevention and counselling guidelines among dental professionals.³⁶ In a mixed methods study that explored the experiences, attitudes, and perspectives in using the TDF in health care implementation initiatives among professionals from multiple disciplines, the authors found that the TDF was a useful framework as it provided a systematic, comprehensive, and theory-derived process to identify barriers to clinical practice change that can help identify target behaviours for change and inform implementation projects.³⁷ Furthermore, the TDF was used because it increased confidence, provided a broader perspective, and has strong theoretical underpinnings. It is hypothesized that the use of the TDF in intervention development is associated with better outcomes but this needs to be confirmed in future studies.³⁵ The TDF could also be used to determine the implementation challenges once the proposed SCI self-management program is implemented.

The current study acknowledges some limitations. It is likely that a selection bias operated in those participants who agreed to take part in the brainstorming sessions – they may have had more interest in SCI self-management than those individuals who decided not to participate. In addition, it should be emphasized that the minority of the focus group participants were individuals with SCI. At the same time, our previous series of studies has emphasized the patient perspective, and thus the current study provides complementary results to these studies. At the same, if there had been a greater number of participants with SCI, we could have validated our previous findings. Furthermore, we did not collect more detailed descriptive information on our participants (e.g. sex, level and completeness of SCI, etc. among the participants with SCI), and are therefore unable to discuss how our results vary by these characteristics. Lastly, the focus group sessions were not audio-recorded. This resulted in an inability to be fully immersed in the data again and the possibility of missing data and a bias in note takers (i.e. only listening to discussions related to the TDF domains).

Conclusion

The current study is, to the best of our knowledge, the only study to apply the TDF for the development of a self-management program. The current study provides complementary results to our previous series of studies on the implementation considerations for the development of a targeted self-management program for individuals with SCI by emphasizing the health care professional/health policy perspective. Based on these studies, the proposed self-management program needs to consider both individual/patient level considerations including the individual's readiness for a self-management program but also various programmatic and environmental considerations including the need for training for those delivering the program, governance and ownership of the program, a business model for sustainability, and issues of privacy and security in the context of on-line delivery. It is anticipated that such a program could not only reduce secondary complications and subsequent inappropriate health care use, but it may also improve the quality of life for individuals with SCI and their caregivers.

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Contributors None.

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Conflicts of interest None.

Ethics approval None.

References

- 1 Dryden DM, Saunders LD, Rowe BH, May LA, Yiannakoulis N, Svenson LW. Utilization of health services following spinal cord injury: a 6-year follow-up study. *Spinal Cord* 2004;42(9):513–25.
- 2 Jaglal SB, Munce SEP, Guilcher SJT, Couris CM, Fung K, Craven BC, *et al.* Health system factors associated with rehospitalisations after traumatic spinal cord injury: a population-based study. *Spinal Cord* 2009;47(8):604–09.
- 3 Munce SEP, Guilcher SJT, Couris CM, Fung K, Craven BC, Verrier M, *et al.* Physician utilization among adults with traumatic spinal cord injury in Ontario: a population-based study. *Spinal Cord* 2009;47(6):470–6.
- 4 Guilcher SJ, Casciaro T, Lemieux-Charles L, Craven C, McColl MA, Jaglal SB. Social networks and secondary health conditions: the critical secondary team for individuals with spinal cord injury. *J Spinal Cord Med* 2012;35(5):330–42.

- 5 McColl MA, Aiken A, McColl A, Smith K. Primary care for people with SCI. In: Eng JJ, Teasell RW, Miller WC, Wolfe DL, Townson AF, Hsieh JTC, Connelly SJ, Mehta S, Sakakibara BM, editors. *Spinal cord injury rehabilitation evidence*. Vancouver; 2010. p. 1–24.
- 6 DeJong G, Hoffman J, Meade M, Bombardier C, Deutsch A, Nemunaitis G, *et al.* Postrehabilitative health care for individuals with SCI: extending health care into the community. *Top Spinal Cord Inj Rehabil* 2011;17(2):46–58.
- 7 Kroll T, Neri MT, Ho P-S. Secondary conditions in spinal cord injury: results from a perspective survey. *Disabil Rehabil* 2007;29(15):1229–37.
- 8 Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. *Patient Educ Couns* 2002;48(2):177–87.
- 9 Barlow JH, Williams RB, Wright CC. Instilling the strength to fight the pain and get on with life: learning to become an arthritis self-manager. *Health Educ Res* 1999;14(4):101–14.
- 10 Lorig K, González VM, Laurent DD, Morgan L, Laris BA. Arthritis self-management program variations: three studies. *Arthritis Care Res* 1998;11(6):448–54.
- 11 Barlow JH, Turner AP, Wright CC. A randomised controlled study of the arthritis self-management programme in the UK. *Health Educ Res* 2000;15(6):665–80.
- 12 Hirsche RC, Williams B, Jones A, Manns P. Chronic disease self-management for individuals with stroke, multiple sclerosis and spinal cord injury. *Disabil Rehabil* 2011;33(13–14): 1136–46.
- 13 Munce SEP, Webster F, Fehlings MG, Straus SE, Jang E, Jaglal SB. Perceived facilitators and barriers to self-management in individuals with traumatic spinal cord injury: a qualitative descriptive study. *BMC Neurology* 2014;14:48.
- 14 Munce SE, Fehlings MG, Straus SE, Nugaeva N, Jang E, Webster F, *et al.* Views of people with traumatic spinal cord injury about the components of self-management programs and program delivery: a Canadian pilot study. *BMC Neurology* 2014;14:209.
- 15 Munce SE, Straus SE, Fehlings MG, Voth J, Nugaeva N, Jang E, *et al.* Impact of psychological characteristics in self-management in individuals with traumatic spinal cord injury. *Spinal Cord* 2016;54(1):29–33.
- 16 Munce SE, Webster F, Fehlings MG, Straus SE, Jang E, Jaglal SB. Meaning of self-management from the perspective of individuals with traumatic spinal cord injury, their caregivers, and acute and rehabilitation managers: an opportunity for improved care delivery. *BMC Neurology* 2016;16:11.
- 17 French SD, Green SE, O'Connor DA, McKenzie JE, Francis JE, Michie S, *et al.* Developing theory-informed behaviour change interventions to implement evidence into practice: a systematic approach using the Theoretical Domains Framework. *Implement Sci* 2012;7:38.
- 18 Cane J, O'Connor D, Michie S. Validation of the theoretical domains framework for use in behaviour change and implementation research. *Implement Sci* 2012;7:37.
- 19 Sandelowski M. Whatever happened to qualitative description? *Res Nurs Health* 2000;23(4):334–40.
- 20 Sandelowski M. What's in a name? Qualitative description revisited. *Res Nurs Health* 2010;33(1):77–84.
- 21 Williams TL, Smith B, Papatomas A. Physical activity promotion for people with spinal cord injury: physiotherapists' beliefs and actions. *Disabil Rehabil* 2016 Dec 5:1–10. [Epub ahead of print]
- 22 Cherryholmes C. Notes on pragmatism and scientific realism. *Educ Res* 1992;21(6):13–7.
- 23 Nowell L. Pragmatism and integrated knowledge translation: exploring the compatibilities and tensions. *Nurs Op* 2015;2(3): 141–48.
- 24 Ide-Okochi A, Tadaka E, Fujimura K. The meaning of self-care in persons with cervical spinal cord injury: a qualitative study. *BMC Neurol* 2013;13:115.
- 25 Holloway I, Wheeler S. *Qualitative research for nurses*. 1996, Malden: Blackwell Science Ltd.
- 26 Guba E, Lincoln Y. *Effective evaluation: improving the usefulness of evaluation results through responses and naturalistic approaches*. 1985, San Francisco: Jossey Bass.
- 27 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3(2):77–101.

- 28 Houlihan BV, Brody M, Everhart-Skeels S, Pernigotti D, Burnett S, Zazula J, *et al.* Randomized trial of a peer-led, telephone-based empowerment intervention for persons with chronic spinal cord injury improves health self-management. *Arch Phys Med Rehabil* 2017;98(6):1067–76.
- 29 McKenzie JE, French SD, O'Connor DA, Grimshaw J, Mortimer D, Michie S, *et al.* Implementing a clinical practice guideline for acute low back pain evidence-based management in general practice (IMPLEMENT): cluster randomised controlled trial study protocol. *Implement Sci* 2008;3:11.
- 30 McKenzie JE, O'Connor DA, Page MJ, Mortimer D, French SD, Walker BF, *et al.* Improving the care for people with acute low-back pain by allied health professionals (the ALIGN trial): a cluster randomised trial protocol. *Implement Sci* 2010;5:86.
- 31 Dyson J, Lawton R, Jackson C, Cheater F. Does the use of a theoretical approach tell us more about hand hygiene behaviour? The barriers and levers to hand hygiene. *J Infection Prev* 2010;12(1):17.
- 32 Boscart VM, Fernie GR, Lee JH, Jaglal SB. Using psychological theory to inform methods to optimize the implementation of a hand hygiene intervention. *Implement Sci* 2012;7:77.
- 33 Francis J, Stockton C, Eccles MP, Johnston M, Cuthbertson BH, Grimshaw JM, *et al.* Evidence-based selection of theories for designing behaviour change interventions: Using methods based on theoretical construct domains to understand clinicians' blood transfusion behaviour. *Br J Heal Psychol* 2009;14(Pt 4): 625–46.
- 34 Francis J, Timmouth A, Stanworth SJ. Using theories of behaviour change to understand transfusion prescribing three clinical contexts in two countries: development work for and implementation trial. *Implement Sci* 2009;4:70.
- 35 Michie S, Pilling S, Garety P, Whitty P, Eccles MP, Johnston M, *et al.* Difficulties implementing a mental health guideline: an exploratory investigation using psychological theory. *Implement Sci* 2007;2:8.
- 36 Amemori M, Korhonen T, Kinnunen T, Michie S, Murtomaa H. Enhancing implementation of tobacco use prevention and cessation counselling guideline among dental providers: a cluster randomised controlled trial. *Implement Sci* 2011;6:13.
- 37 Phillips CJ, Marshall AP, Chaves NJ, Jankelowitz SK, Lin IB, Loy CT, *et al.* Experiences of using the Theoretical Domains Framework across clinical environments. *J Multidisc Healthcare* 2015;8:139–46.