



Medication adherence for persons with spinal cord injury and dysfunction from the perspectives of healthcare providers: A qualitative study

Sara J. T. Guilcher, Amanda C. Everall, Tejal Patel, Tanya L. Packer, Sander L. Hitzig & Aisha K. Lofters

To cite this article: Sara J. T. Guilcher, Amanda C. Everall, Tejal Patel, Tanya L. Packer, Sander L. Hitzig & Aisha K. Lofters (2019) Medication adherence for persons with spinal cord injury and dysfunction from the perspectives of healthcare providers: A qualitative study, *The Journal of Spinal Cord Medicine*, 42:sup1, 215-225, DOI: [10.1080/10790268.2019.1637644](https://doi.org/10.1080/10790268.2019.1637644)

To link to this article: <https://doi.org/10.1080/10790268.2019.1637644>



© 2019 The Author(s). Published with license by Taylor & Francis Group, LLC



Published online: 01 Oct 2019.



Submit your article to this journal [↗](#)



Article views: 241



View related articles [↗](#)



View Crossmark data [↗](#)

Special Article

Medication adherence for persons with spinal cord injury and dysfunction from the perspectives of healthcare providers: A qualitative study

Sara J. T. Guilcher ^{1,2,3}, Amanda C. Everall ¹, Tejal Patel ^{4,5}, Tanya L. Packer ⁶, Sander L. Hitzig ^{2,7,8}, Aisha K. Lofters ⁹

¹Leslie Dan Faculty of Pharmacy, University of Toronto, Toronto, Canada, ²Rehabilitation Sciences Institute, Faculty of Medicine, University of Toronto, Toronto, Canada, ³Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto, Canada, ⁴School of Pharmacy, University of Waterloo, Kitchener, Canada, ⁵Department of Family Medicine, DeGroot School of Medicine, McMaster University, Hamilton, Canada, ⁶School of Occupational Therapy and Health Administration, Dalhousie University, Halifax, Canada, ⁷St. John's Rehab Research Program, Sunnybrook Research Institute, Sunnybrook Health Sciences Centre, Toronto, Canada, ⁸Department of Occupational Science and Occupational Therapy, Faculty of Medicine, University of Toronto, Toronto, Canada, ⁹Department of Family and Community Medicine, St. Michael's Hospital, University of Toronto, Toronto, Canada

Context: People with spinal cord injury and dysfunction (SCI/D) often take multiple medications (*i.e.* polypharmacy) to manage secondary health complications and multiple chronic conditions. Numerous healthcare providers are often involved in clinical care, increasing the risk of fragmented care, problematic polypharmacy, and conflicting health advice. These providers can play a crucial role in assisting patients with medication self-management to improve medication adherence.

Design: A qualitative study involving telephone interviews, following a semi-structured guide that explored healthcare providers' conceptualization of factors impacting medication adherence for persons with SCI/D. The interviews were transcribed and analyzed descriptively and interpretively using a constant comparative process with the assistance of data display matrices. Analysis was guided by an ecological model of medication adherence.

Setting and participants: Thirty-two healthcare providers from Canada, with varying clinical expertise.

Intervention: Not Applicable.

Outcome measures: Not Applicable.

Results: Providers identified several factors that impact medication adherence for persons with SCI/D, which were grouped into micro (medication and patient-related), meso- (provider-related) and macro- (health system-related) factors. Medication-related factors included side effects, effectiveness, safety, and regimen complexity. Patient-specific factors included medication knowledge, preferences/expectations/goals, severity and type of injury, cognitive function/mental health, time since injury, and caregiver support. Provider-related factors included knowledge/confidence and trust. Health system-related factors included access to healthcare and access to medications. While providers were able to identify several factors influencing medication adherence, micro-level factors were the most frequently discussed.

Conclusion: Findings from this study indicate that strategies to optimize medication adherence for persons with SCI/D should be multi-faceted.

Keywords: Medication management, Medication adherence, Patient preference, Polypharmacy, Spinal cord injury

Correspondence to: Sara J. T. Guilcher, Leslie Dan Faculty of Pharmacy, 144 College Street, Toronto, ON, Canada, M5S 3M2; Ph: 416-946-7020. Email: sara.guilcher@utoronto.ca

Introduction

Spinal cord injury and dysfunction (SCI/D) can result in permanent disability and negatively impacts an

individual's physical, mental, and social wellbeing.^{1,2} Persons with SCI/D may experience multiple secondary health complications³⁻⁵ and comorbid conditions.⁶⁻⁸ As a result, treatment plans are often complex,^{9,10} involving the concomitant use of multiple medications (*i.e.* polypharmacy),¹¹⁻¹⁴ which often include high-risk prescription drugs (*e.g.* opioids, benzodiazepines).^{14,15} While research is limited,¹⁶ rates of polypharmacy range from 31% to 87%.¹²⁻¹⁴ Polypharmacy is commonly associated with adverse drug events,¹³ reduced medication adherence,¹⁷ increased healthcare costs,¹⁸ and lower quality of life.¹⁹ A recent retrospective study found that individuals with SCI/D and polypharmacy were at a greater risk of experiencing an adverse drug event compared to a non-SCI/D control population.²⁰

The complexity of medication regimens can adversely impact medication adherence.²¹ Adherence involves patients and healthcare provider coordination on timely initiation and discontinuation of medications, as well as consistent implementation of the dosing regimen.²² Appropriate medication management and optimal medication adherence are dependent upon the functional ability to administer medication.²³ Functional ability includes skills such as correctly identifying medications, timing doses, opening medication containers/packaging, and withdrawing and administering appropriate amounts of medication.^{24,25} Poor medication management and non-adherence can result in increased emergency department visits,²⁶ re-hospitalization, and morbidity.²⁷ Although medication adherence is a primary determinant for the successful treatment of chronic conditions,^{27,28} approximately half of all persons with chronic conditions in developed countries do not take their medications as prescribed.^{27,29}

The high instances of polypharmacy^{9,13} and health and social complexities¹ in the SCI/D population underscore the need for further research into medication adherence. Through effective communication and patient-centered care, healthcare providers can play a pivotal role in improving medication adherence and self-management behaviors of patients experiencing polypharmacy.³⁰⁻³² However, to the best of our knowledge, research describing healthcare providers' beliefs and attitudes about, and experiences with, medication adherence among persons with SCI/D has not been conducted. Therefore, the primary purpose of this study was to address this gap.

Materials and methods

Design, eligibility, and recruitment

Using qualitative methods, individual interviews were conducted with healthcare providers (hereafter referred

to as providers). Eligible participants were English speaking providers who practiced in Canada, and provided care for at least one person with SCI/D. Study recruitment materials were shared by the researchers' circle of contacts, professional organizations and associations, and through social media. Interested and eligible individuals were sent the study information and consent form. Participants were purposefully selected during screening for diversity in professions (*e.g.* physicians, pharmacists, rehab professionals). Written or verbal consent was obtained from all participants before interviews were conducted. This study received Research Ethics Board approvals from the University of Toronto (#34063) and the University of Waterloo (#31790).

Data collection

Providers were interviewed by telephone between March and December 2018 following a semi-structured interview guide. Topics discussed included experiences and roles associated with medication management for persons with SCI/D including barriers and facilitators. A clinical and demographical survey was administered at the beginning of each interview. All interviews were audio-recorded. The interviewers wrote reflexive notes following each interview.

Data analysis

The audio recordings were transcribed verbatim and cleaned of all identifying information. Descriptive data analysis of the transcripts occurred concurrently with data collection. Interviews were conducted until thematic saturation was achieved (*i.e.* no new concepts identified in interviews).³³ Components of the Qualitative Analysis Guide of Leuven were used to ensure rigor and integrity of analysis.³⁴ Transcripts from different healthcare professionals were reviewed independently by all research team members to identify common high-level concepts. These concepts were discussed in team meetings and were used to create a preliminary coding framework. Revisions to the coding framework were made as new concepts emerged from subsequent interviews until a final framework was agreed upon by the team. Two team members independently coded two transcripts and compared coding line by line. Any discrepancies were discussed until consensus was achieved. The remaining transcripts were coded independently by the same two team members. NVivo 11 software was used to facilitate organization of data. Once all data was coded, comparisons were made, stratified by profession, using data display matrices following an iterative constant comparative

approach.³⁵ Given the multi-dimensional nature of adherence, study findings are presented using an adapted version of Bronfenbrenner’s ecological model, which identifies different levels (*i.e.* micro, meso and macro levels) of medication non-adherence risk factors.³⁶

Results

Thirty-two participants were interviewed (see Table 1). The majority of participants were community or hospital pharmacists (n = 12); next highest were physicians (n = 10). The majority of the sample was female (n = 20), had a median of 11 years of clinical experience (range 1–37), and worked in Ontario (n = 30). Healthcare providers described micro- (medication and

patient-specific), meso- (provider-specific) and macro- (health system specific) level factors that influenced medication adherence (see Table 2).

Micro-level factors

Micro-level factors were the most abundantly described and related to aspects of both medications and characteristics of patients (see Table 3).

Medication-related factors

Side effects: All providers, with the exception of one care coordinator, explained how medication side effects could decrease medication adherence for individuals with SCI/D. Providers described patients changing the timing of medications, decreasing doses, or more often, stopping medications entirely because of intolerable side effects. According to providers, these medication changes were often done without provider consultation.

According to participants, individuals with SCI/D became non-adherent to medications when the medication side effects interrupted patient participation in therapy or, more generally, “engaging out and about” in the community (C14, Occupational Therapist). Common examples of such interruptions involved pain and anti-spasticity medications (*e.g.* oxycodone, gabapentin and baclofen), which resulted in undesirable side effects such as fatigue, dizziness, confusion, and constipation.

Perceived effectiveness: Perceived medication effectiveness was another medication-specific factor that providers identified as impacting adherence for individuals with SCI/D. For example, a specialist physician (C30) described how patients’ perceptions of improved symptoms were directly linked to their adherence to the treatment.

Table 1 Socio-demographic and clinical characteristics of participants (N = 32).

Participant characteristic	n (%)
<i>Type of profession</i>	
• Physician	10 (31.3)
• Pharmacists	12 (37.5)
• Rehabilitation Professional	7 (21.9)
• Other	3 (9.4)
<i>Years of experience</i>	
• 0–5	7 (21.9)
• 6–15	13 (40.6)
• 16 or more	9 (28.1)
• Unknown*	3 (9.4)
<i>Current SCI/D caseload</i>	
• Less than 5%	16 (50)
• 6% to 49%	9 (28.1)
• 50% or more	3 (9.4)
• Unknown*	4 (12.5)
<i>Sex</i>	
• Male	12 (37.5)
• Female	20 (62.5)

Note: Due to rounding to one decimal, some percentages may not add up to 100.

*Participants did not provide an answer to this question.

Table 2 Factors identified by healthcare providers that influence medication adherence among individuals with spinal cord injury and dysfunction (SCI/D).

	Micro: Patient-specific factors	<ul style="list-style-type: none"> • Medication knowledge • Preferences, expectations, and goals • Severity of SCI/D injury, cognitive function/mental health, time since injury • Caregiver support
	Micro: Medication-related factors	<ul style="list-style-type: none"> • Side effects • Perceived effectiveness • Perceived safety • Complexity of medication regimen
	Meso: Clinician-related factors	<ul style="list-style-type: none"> • Knowledge and confidence with SCI/D medications and common complications • Patient trust
	Macro: Health system factors	<ul style="list-style-type: none"> • Accessibility and availability of healthcare services • Accessibility and availability of medications

Table 3 Micro level factors influencing medication adherence for individuals with spinal cord injury and dysfunction (SCI/D).

Medication-related factors	
Side effects	A care coordinator (CC01) explained that individuals with SCI/D “don’t always go back to their physician” with concerns about medication side effects and an occupational therapist (C18) described some patients “finding they have side effects and they just don’t know who to turn to and they just stop”. An occupational therapist (C13) explained that anti-spasticity medications “make people very drowsy [so] sometimes they’ll skip doses of it” and a community pharmacist (C20) described patients reducing doses of oxycodone “because of the constipation”.
Perceived effectiveness	“Number one, whether they actually see a benefit or not and sometimes with some medications, it’s clear that you see benefits. For instance, if you take your medications for spasticity, then you really see it. But sometimes if you actually prescribe something that they don’t necessarily see the direct benefits, then it’s hard for them to be compliant unless they really understand what that’s for.” [C30, Specialist Physician] “If they’re not getting their refills or if they’re not coming back on a regular basis, that’s something that you do have to monitor or that’s something that would signify that [the medication is] not working.” [C02, Community Pharmacist]
Perceived safety	“I had a client who became addicted to their opioids that they were taking and so that was tricky. They went off the opioids, but they were in a lot of pain, so that was a really tricky situation because they were addicted and they were taking too much. So there was a little bit of consulting with their family doctor on that.” [CC02, Care Coordinator]
Regimen complexity	“I think number one [for medication adherence] would be like the frequency. So, I think – people can take things once a day, but I think you are really pushing it when you are asking them to take things twice and three times a day ... The other thing that I find is like the actual volume of pills. So, when I can I will also look for opportunities to combine medications so that there would be less pill burden.” [C24, Family Physician] “... in terms of I guess how inconvenient it is ... like if it’s something they were taking every four hours, you kind of have to stop whatever you’re doing to take the medication versus if you can give them something that’s long-acting that you only take twice a day.” [C07, Hospital Pharmacist] “... if you have to do something five times a day, you’ll less likely to be compliant than if it’s just twice. So, the pharmacist can often help with that.” [C28, Specialist Physician]
Patient-specific factors	
Medication knowledge	“So, if you don’t know why you are taking something, it’s very difficult to think, ‘okay, well I need to take this.’” [C04, Hospital and Community Pharmacist] When asked about factors that impact medication adherence, a family physician (C15) listed “understanding how to use the medication” and “understanding, in general, the importance of the medication.”
Preferences, expectations, and goals	A case coordinator’s patients with SCI/D felt it was “too many medications” so they “just start[ed] cutting things out.” [Case Coordinator CC01] “... they don’t want to be [taking] medications long-term, so that influences how much they take, when they take it and how long they take it.” [C27, Physiotherapist] “Expectations are a big thing. Specifically, like if they are taking something for a medication – like a pain medication where you can see the results or you’re expecting a change and you are able to notice that, it’s a lot different than if you’re treating like hypertension where, you know, they can’t really see the results and so, the expectations of what they are going to get out of the medication.” [C05, Community Pharmacist] “Normally [goals involve] quality of life. A lot of [patients with SCI/D] do mention pain relief ... A lot of them are – want to be able to just continue on with the day without pain.” [C02, Community Pharmacist] “... I think in the longer term it probably also, depends on the patients’ goals for themselves and whether they start valuing quality of care over quantity, or yeah, quality of life versus quantity of life, especially if their condition is starting to deteriorate. Sometimes they may not want to continue certain medications because of their long terms goals.” [C26, Family Physician] “So, medication compliance ... so I’ve noticed that there is one medication, and I forgot the name, but it is one that they have to take and they’re not able to eat their meal after. And one of the things that impacts them taking that one on a regular basis is that they have to wait a certain amount of time before they’re able to eat and I think it’s like two hours or so. So, I guess the activities that they have to conform to, or the conditions while taking their medication.” [C13, Occupational Therapist]

Severity of injury, cognitive function/mental health, and time since injury	<p>" ... if the injury is minor ... then it's not totally affecting their daily life, they may only use the medication when things get a little worse ... Even though they may be supposed to take it on a daily basis ... if it's not bothering them, they may not [take it] ... Yeah, so the less severe the injury is, the more prone ... they are to not adhering, essentially." [C10, Community Pharmacist]</p> <p>"[For] traumatic accidents, spinal cord injury and brain injury can go hand-in-hand ... [individuals with brain injuries sometimes have] difficulty remembering to take their medications [and might be] ... less likely to take their medications ... forget to take [their medications or] think it doesn't matter if they take [their medications]." [CC02, Case Coordinator]</p> <p>"[Factors decreasing medication adherence include] low manual dexterity, or swallowing difficulty, or an artificial intake, like a G-tube." [C16, Family Physician]</p> <p>"[I focus on improving] fine motor skills to pick up pills ... physically opening pill boxes ... " [C18, Occupational Therapist]</p>
Caregiver Support	<p>" ... list of mental health issues, the post-trauma – PTSD and depression and anxiety [was] really impeding [adherence]." [C14, Occupational Therapist]</p> <p>"I guess the level of support because I feel like most – like the patients that I find that are most compliant are people or patients who have someone who is able to kind of provide that support. Whether it's just like, whether it's the mom who, you know, is always at home and is kind of the one person providing the medication 24 hours." [C07, Hospital Pharmacist]</p> <p>" ... depending on the patients, [caregivers] may play quite a significant role in terms of medication administration or reminders or even things like, you know, obtaining the prescription from the pharmacy ... " [C24, Family Physician]</p> <p>"And sometimes it's – it's important to address their non or informal caregivers on motivational speaking. The patient may be depressed, for example, and – or they may be unwilling to take their medication, in which case it is important for people in their life to help them stay motivated in order to adhere to the optimum medication therapy regimen." [C03, Community Pharmacist]</p> <p>" ... oftentimes it's someone's support network that might be saying, you know, 'I don't feel that this is important.' So, it's not just the patient." [C28, Specialist Physician]</p> <p>"[Caregivers] may get confused and give the wrong [medications]." [C14, Occupational Therapist]</p> <p>"[Caregivers] might be unavailable for some reason, then [the patient] might not be able to be as compliant as they would like." [C19, Occupational Therapist]</p>

Some community pharmacists described using their medication dispensing software to track late or early medication “pick-ups” from the pharmacy, which were considered proxies for patient medication adherence and potential indicators of poor medication effectiveness. These pharmacists interpreted early pick-ups as insufficient medication doses and lack of pick-up as medication ineffectiveness.

Perceived safety: Safety was the least discussed medication-related factor impacting adherence, and focused mostly on patients’ fear of addiction to pain medications. As a consequence of this fear, some providers discussed that patients may refuse to fill a prescription, decrease doses, or independently wean off medications. However, not all providers felt that this fear of addiction was justified. One community pharmacist (C08) described how she tried to alleviate her patients’ fear of addiction to pain medications by explaining the medication’s proven safety in the general public and the medication titrating process (how the dose of the medication will be increased or decreased).

Some providers also talked about patients who experienced addiction to medications. For example, a care coordinator (CC02) shared her experiences working with a person with SCI/D who became addicted to an opioid medication and the subsequent difficulty her patient encountered with pain during a provider-monitored deprescribing process.

Drug regimen complexity: Many providers discussed how complex medication regimens, involving dosing, timing, and the number of medications, could decrease medication adherence for patients with SCI/D. For example, a family physician (C24) explained how the frequency and quantity of pills negatively impacted adherence, so she minimized the dosing frequency and combined multiple medications into one pill to decrease the pill burden. Pharmacists and physicians explained that the timing of the medications could sometimes impede daily activities, resulting in decreased medication adherence. A common solution was to increase medication doses or substitute with longer-lasting medications.

Patient-specific factors

Medication knowledge: Overall, most providers indicated that the medication knowledge of individuals with SCI/D could impact adherence to medications. Providers agreed that patients who were informed about the indication, the pharmacodynamics (biological and physiological effects), how to take medications, and the dosing of their medications were more likely to adhere to their regimen.

Patient preferences, expectations, and goals: Providers described how many individuals with SCI/D preferred to avoid prescription medications, which was thought to decrease medication adherence. Perceived patient preferences included avoiding prescription medications all together, decreasing the number of prescription medications taken concomitantly, or decreasing the duration of prescription medications. A few providers also described how experiencing a therapeutic benefit from a medication was directly linked to patients’ expectations of the medication. When patients’ expectations were not met, this could impact their medication adherence.

Providers also discussed how patient goals impacted their clinical activities, such as prescribing/deprescribing medications and providing information/education. Some physicians explained that their patients’ goals relating to quality of life were taken into consideration when stopping a medication. For example, a physician (C26) described the balance of quantity versus quality of life, and how this balance could impact a patient’s decision to continue taking a medication.

Occupational therapists explained that patients with SCI/D preferred medications to fit into their lifestyles and daily routines, and how sometimes, despite the therapeutic benefit of a medication, patients choose not to take the medication if the timing was inconvenient. This patient preference was described by an occupational therapist (C13) using an example of how medications could interfere with meal routines, thus impacting quality of life.

Severity of injury, cognitive function/mental health, and time since injury: Overall, there was agreement among healthcare providers on the injury-related factors that impact adherence: severity and type of the injury; cognitive function/mental health; and time since injury.

The type (e.g. traumatic versus non-traumatic) of the injury was identified as a factor that impacted medication adherence for individuals with SCI/D. For example, some providers felt that patients with less severe injuries were generally less adherent because patients perceived their injury symptoms to be mild enough to not necessitate medications. Providers explained how the severity (i.e. tetraplegia versus paraplegia) of injury could impact physical mobility and dexterity, which could limit patients’ ability to physically take medications and therefore decrease medication adherence.

A few providers focused on the impact of SCI/D on patients’ cognitive function/mental health, which was thought to have the potential to decrease adherence. Providers generally agreed that untreated mental

health concerns such as post-traumatic stress disorder (PTSD), depression, anxiety, bi-polar disorder, and dual personality disorders could result in decreased adherence. Further, providers explained that the amount of time post-injury could impact medication adherence, describing individuals with recent SCI/D injuries being more likely to have depression or “feel very down” (C08, Community Pharmacist), which could decrease adherence because patients may lack the motivation to take their medications.

Caregiver support: Almost all providers explained how caregiver support influenced medication adherence for individuals with SCI/D, especially when the individual had limited upper body movement. The caregiver’s influence was viewed by providers’ as potentially positive or negative, depending on the caregiver and their relationship with the patient. For example, a hospital pharmacist (C07), who worked predominantly with youth, explained that with her population, having a supportive caregiver was paramount to medication adherence because the caregiver was generally the one administering the medications. Most family physicians and community pharmacists agreed, explaining that caregivers assisted in picking up medications from the pharmacy, reminding persons with SCI/D to take their medications, physically administering the medication, or providing emotional support using motivational speaking to encourage medication adherence. Most rehabilitation specialists and specialist physicians agreed that caregivers had a positive influence on medication adherence; however, they also noted that caregivers could negatively influence adherence, either intentionally, by withholding medications when they didn’t feel it was needed, or unintentionally, by

forgetting or being unavailable to administer a medication at the proper time.

Meso-level factors

Two meso-level (provider-specific) factors were identified by providers as impactful on medication adherence for individuals with SCI/D (see Table 4).

Providers’ knowledge and confidence: Most providers felt that their clinical knowledge and confidence with the SCI/D condition and SCI/D-related medications indirectly influenced medication adherence of their patients by influencing the amount of medication-specific information they were able to share with their patients. For example, a nurse (C12) explained that her knowledge relating to medications for individuals with SCI/D enabled her to provide education to patients, which was believed to increase adherence. This provider described having more time to spend with patients to explain the therapeutic effects of the medications. Conversely, a physician (C15) felt that patients would not be able to differentiate between knowledgeable and unknowledgeable providers as long as the provider sounded confident. He felt that portraying clinical confidence was important when getting ‘buy in’ from the patient when a medication was initiated.

Building patient trust: Almost all participants interviewed discussed the importance of building trust, which led to improved information sharing, more informed patients, and ultimately improved medication adherence. For example, community pharmacists talked about establishing trust, often describing their interactions with individuals with SCI/D as “family-like”. A family physician (C15) explained that the subset of patients with SCI/D who have “congenital

Table 4 Meso level factors influencing medication adherence for individuals with spinal cord injury and dysfunction (SCI/D).

Provider-specific factors	
Knowledge and confidence	<p>“I think sometimes it does help to influence [adherence], or at least with my knowledge [because] I do have a little bit more time than a doctor to explain what and how each medication works with them and the combination of medications and how that has a therapeutic effect on their bodies. So, sometimes, depending again on the client’s state of mind, it will help them to see it more or even things like bowel treatments and bowel routines, knowing how the enema works can help with compliance.” [C12, Nurse]</p> <p>“I mean I guess in theory if I didn’t know what to prescribe, then I wouldn’t prescribe it and so they wouldn’t use it. So, I guess to that extent, yes. Like, if you’re talking though like you’re saying how knowledgeable I am like impacts the level of buy-in, I don’t think so. I think – I don’t think patients necessarily have a great sense of you know, whether you do or don’t know what you’re talking about. I think as long as you know, you come across as sounding confident, I’m not sure that they know whether you do or don’t really have great knowledge.” [C15, Family Physician]</p>
Building patient trust	<p>“... [creating a] family atmosphere [with the patient and their caregivers to create] this background bond ... [so they] don’t feel scared to be honest with you.” [C08, Community Pharmacist]</p> <p>“... sit[ting] all together talking like a family.” [C06, Community Pharmacist]</p> <p>“... their lives have been so medicalized that they really don’t have much trust in healthcare providers and it’s more like they don’t want to take it and I think they’re like sort of exerting some autonomy by sort of deciding not to take it.” [C15, Family Physician]</p>

conditions” or experienced their injury “from a young age” often had more issues with medication adherence because their life has been medicalized resulting in decreased trust in providers. This physician felt that such patients might choose not to take their medications as a show of autonomy or self-control in their lives.

Macro-level factors

Participants identified two main macro-level (health systems) factors that influenced adherence for individuals with SCI/D (see Table 5).

Availability and accessibility of healthcare services: Many providers understood that their patients with SCI/D had undergone a major transition following their injury. Most of these patients had new healthcare needs, which required them to learn the necessary skills to navigate the healthcare system in order to access providers and treatments. Being a new user of the system, providers considered many of these patients to be likely to have poor medication adherence due to transportation difficulties, long wait-times for appointments, inaccessibility of healthcare facilities (including organizational resources for assessment), and insufficient government funding for some health services. Each of these factors limited access to providers for medication refills, medication reviews, or to ask questions about their medications.

Many providers described using alternatives to in-person appointments to improve healthcare access for individuals with SCI/D, such as video or telephone

appointments, email communications, and home visits. For example, a hospital and community pharmacist (C04) described the importance of home visits for services such as medication reviews for this population in order to have discussions with patients about their medications instead of simply delivering the medications.

Lack of government funding for health services was another factor that participants identified as impactful on patients’ medication adherence. Pharmacists and physicians both felt that adherence-focused medication reviews, which aim to improve patient medication-knowledge and adherence, were underfunded. In addition, the need for more personal support worker/attendant funding was highlighted by occupational therapists to ensure timely administration of medications.

Availability and accessibility of medications: Providers also described how cost, insurance policies, refill policies, and home delivery services impact medication adherence for individuals with SCI/D. In general, prohibitive costs and inadequate insurance were thought to decrease medication adherence, while refill policies and delivery services had the capacity to increase adherence.

Medication cost was the most frequently discussed macro-level factor, as providers felt that some patients took fewer pills when a medication was not covered by their drug plan. Providers understood that individuals with SCI/D who were not eligible for public drug plans and did not have private plans may be more likely to be non-adherent due to medication costs. A few providers also discussed pharmacist and physician

Table 5 Macro level factors influencing medication adherence for individuals with spinal cord injury and dysfunction (SCI/D).

Health system factors	
Availability and accessibility of services	<p>“ ... it can be you know, very overwhelming, I find. Particularly affecting sort of you know, sort of my clients who are males and they’re in their 30s, 40s even 50s who [prior to] their spinal cord injury had, you know, little to no interaction with the healthcare system. And now, you know have major healthcare needs. I find, you know for a lot of them, they kind of struggle in the beginning in terms of wrapping their head around it. I find for people who have been connected with the healthcare system longer, it’s sort of not as jarring.” [C15, Family Physician]</p> <p>“With this population, if it’s the inability of them sometimes to maybe get into the pharmacy so that they are not getting the one-on-one counselling, so they can fall through the cracks. So, someone, you know, everybody just assumes it’s easier just to keep sending the medication [medication delivery] versus anyone going out having the discussion with them about it are big barriers [to supporting patients with SCI/D with their medications].” [C04, Hospital and Community Pharmacist]</p> <p>“ ... it’s hard to find [personal support] service that can service the number of hours that they require.” [C14, Occupational Therapist]</p> <p>“ ... the PSW [personal support worker] is the one actually administering the medication.” [C18, Occupational Therapist]</p>
Availability and accessibility of medications	<p>“ ... when medications aren’t covered, especially the ones for just physical pain treatment, that can really inhibit the amount the patient can actually take or what they will be willing to take and a lot of times it’s a little frustrating I think for us, as well, because we know that they might need these medications and they might not be necessarily willing because of the cost.” [C02, Community Pharmacist]</p> <p>“ ... my office will fax the prescription over to the pharmacy so that [patients with SCI/D] don’t have to take it in ... and the pharmacy will deliver the medications.” [C15, Family Physician]</p>

refill policies and home delivery services as other factors that influenced medication adherence for individuals with SCI/D. For example, a family physician (C15) described frequently faxing medication prescriptions to the pharmacy and having the pharmacy deliver medications to ensure consistent use of medications.

Discussion

To our knowledge, this qualitative study is the first to have explored providers' perceptions of factors that influence medication adherence for persons with SCI/D. Overall, providers identified many different factors that influenced medication adherence, with the majority of the factors being at the micro-level. Relatively fewer factors were identified at the meso- or macro-levels. Despite the majority of factors being related to characteristics of patients (*e.g.* medication knowledge, severity of injury, comorbidities) or medications (*e.g.* side effects, complexity of regimen), providers identified several intersecting factors at the meso- and macro-levels (*e.g.* building trust, spending more time with patients, improving accessibility of providers, and access to medications) to help optimize medication adherence. Many of these factors align with factors previously identified relating to adherence for other chronic conditions.^{27,28}

Of the medication-specific factors, side effects of medications were commonly described as negatively impacting adherence, as well as the lack of immediate bio-physiological feedback of the effectiveness of medications. To address these issues, providers spoke of the importance of creating more opportunities for patients to interact with healthcare providers (virtual or in-person) to help establish trusting relationship with patients. Spending more time with patients and caregivers could help increase their respective knowledge of their medications, as well as provide opportunities to discuss any concerns. Previous research among persons with multimorbidity has shown that difficulties seeking information, interacting with healthcare providers, and accessing healthcare resources were common barriers that result in decreased medication adherence.³⁷ However, healthcare providers can improve medication adherence and self-management behaviors by fostering collaborative relationships and meaningfully engaging with patients and their caregivers.^{30–32}

Interestingly, participants who were from rehabilitation backgrounds commonly spoke about encouraging patients to self-advocate when speaking with physicians about medication concerns. Competing medical demands during appointments with constrained time may restrict opportunities for patients to speak about medication concerns. Previous research for persons

with SCI/D has highlighted challenges with access to primary care (*e.g.* transportation, timely appointments).^{38,39} Traditional fee-for-service primary care models with time restraints on clinical encounters (*e.g.* one problem per visit) are problematic for persons with multimorbidity.⁴⁰ Our findings reinforce the importance of holistic patient-centered care,⁴¹ that reflect the goals and needs of patients and caregivers in a welcoming non-time limited environment.

Given the accessibility challenges identified in our study, community pharmacists are well positioned to play a leading role for medication management among persons with SCI/D. Community pharmacists are one of the most accessible healthcare providers for persons living in the community, especially those with disabilities, and as such, providing more educational opportunities for pharmacists to conduct medication reviews among persons with SCI/D may be warranted. Our results reinforce the importance for clinicians to have the knowledge and confidence related to medications for person with SCI/D.

Our findings also identified that pharmacists reported using prescription refill behavior as a proxy for adherence. While this may be an acceptable method to gather information on medication-taking behavior, having open conversations with patients and caregivers are the more recommended strategies.⁴² Ongoing discussions with patients and caregivers may be more helpful to build trusting relationships for optimal clinical care. Leveraging technology may also improve communication with patients thereby enhancing access to healthcare providers in addition to promoting adherence among persons with disability.⁴³ As an example, a recent pilot study in the United States examined the impact of interactive text-messaging and reminder follow up phone calls to persons with more than one chronic condition and found the intervention improved adherence.⁴³

Another key finding from this research is the impact mental health may have on adherence. Healthcare providers identified that persons with SCI/D may have co-occurring mental health issues such as depression and anxiety, which may impact their abilities to cognitively manage the complicated medication regimens that are often prescribed. A previous meta-analysis has shown that persons with chronic conditions and depression have 1.76 times higher odds of being non-adherent to their medications compared to those without depression.⁴⁴ Healthcare providers should be aware of this vulnerability for persons with SCI/D, and consider screening for mental health concerns during regular visits and medication reviews.

Limitations of the study

This study has some limitations to note. We experienced challenges recruiting physicians, and relied heavily on our snowball sampling strategy, which meant that our physician participants likely had more clinical expertise with SCI/D compared to the general physician population. Further, despite our best efforts to interview different types of providers, few specialist physicians (e.g. urologists, physiatrists) participated in the study. Future research would be warranted to further explore specialists' perceptions of factors that influence adherence, as well as other general practitioners with less experience of the SCI/D population. The majority of our participants were recruited from one province, thus future research would be warranted in other jurisdictions with different healthcare system structures.

Conclusion

Overall, healthcare providers identified many different factors that influenced medication adherence for individuals with SCI/D. While this work highlighted the perspective of healthcare providers in regards to medication adherence, it is equally important to understand patients' perspectives. Future research by our team will explore the lived experiences of individuals with SCI/D and medication management. More research is warranted to explore how policies and practice changes may assist with creating more person-centered, clinical engagement opportunities around medication adherence and medication management more broadly.

Acknowledgements

The authors would like to acknowledge the Ontario Pharmacy Evidence Network (OPEN) for supplying a database from which Ontario pharmacists were recruited. The authors would also like to thank Stephanie Cimino for assistance with data collection and coding, Maliha Asif for assistance with the literature review, and Lauren Cadel for assistance with thematic analyses and reviewing drafts of the manuscript.

Disclaimer statements

Funding This project was funded by the Craig H. Nielsen Foundation (Psychosocial Research Pilot Grant #441259) and the Connaught New Investigator Award (University of Toronto). Dr. Guilcher is supported by a Canadian Institutes for Health Research Embedded Clinician Scientist Salary Award on Transitions in Care (2016-2020).

Conflicts of interest The authors have no conflicts to declare.

ORCID

Sara J. T. Guilcher  <http://orcid.org/0000-0002-9552-9139>

Amanda C. Everall  <http://orcid.org/0000-0002-8270-6925>

Tejal Patel  <http://orcid.org/0000-0003-3002-8306>

Tanya L. Packer  <http://orcid.org/0000-0003-4831-7691>

Sander L. Hitzig  <http://orcid.org/0000-0002-9139-9250>

Aisha K. Lofters  <http://orcid.org/0000-0002-7322-0894>

References

- DeVivo MJ, Chen Y. Trends in new injuries, prevalent cases, and aging with spinal cord injury. *Arch Phys Med Rehabil.* 2011; 92(3):332–8.
- Hitzig SL, Tonack M, Campbell KA, McGillivray CF, Boschen KA, Richards K, et al. Secondary health complications in an aging Canadian spinal cord injury sample. *Am J Phys Med Rehabil.* 2008;87(7):545–55.
- Jensen MP, Kuehn CM, Amtmann D, Cardenas DD. Symptom burden in persons with spinal cord injury. *Arch Phys Med Rehabil.* 2007;88(5):638–45.
- Kroll T, Neri MT, Ho PS. Secondary conditions in spinal cord injury: results from a prospective survey. *Disabil Rehabil.* 2007; 29(15):1229–37.
- Noreau L, Proulx P, Gagnon L, Drolet M, Laramee M-T. Secondary impairments after spinal cord injury. *Am J Phys Med Rehabil.* 2000;79(6):526–35.
- Cragg JJ, Noonan VK, Dvorak M, Krassioukov A, Mancini GBJ, Borisoff JF. Spinal cord injury and type 2 diabetes. *Am Acad Neurol.* 2013;81:1864–8.
- Cragg JJ, Noonan VK, Krassioukov A, Borisoff J. Cardiovascular disease and spinal cord injury. *Am Acad Neurol.* 2013;81:723–8.
- Kennedy P, Rogers BA. Anxiety and depression after spinal cord injury: a longitudinal analysis. *Arch Phys Med Rehabil.* 2000; 81(7):932–7.
- Jensen EK, Biering-Sorensen F. Medication before and after a spinal cord lesion. *Spinal Cord.* 2014;52(5):358–63.
- The Multidisciplinary Association of Spinal Cord Injury Professionals. Management of the Older Person with a New Spinal Cord Injury. Middlesex: The Multidisciplinary Association of Spinal Cord Injury Professionals; 2010.
- Guilcher SJT, Hogan ME, Calzavara A, Hitzig SL, Patel T, Packer T, et al. Prescription drug claims following a traumatic spinal cord injury for older adults: a retrospective population-based study in Ontario, Canada. *Spinal Cord.* 2018;56(11):1059–68.
- Hwang M, Zebracki K, Vogel LC. Medication profile and polypharmacy in adults with pediatric-onset spinal cord injury. *Spinal Cord.* 2015;53(9):673–8.
- Kitzman P, Cecil D, Kolpek JH. The risks of polypharmacy following spinal cord injury. *J Spinal Cord Med.* 2017;40(2):147–53.
- Patel T, Milligan J, Lee J. Medication-related problems in individuals with spinal cord injury in a primary care-based clinic. *J Spinal Cord Med.* 2017;40(1):54–61.
- Siddall PJ. Management of neuropathic pain following spinal cord injury: now and in the future. *Spinal Cord.* 2009;47(5):352–9.
- Cadel L, Everall AC, Hitzig SL, Packer TL, Patel T, Lofters AK, et al. Spinal cord injury and polypharmacy: a scoping review. *Disabil Rehabil.* 2019. doi:10.1080/09638288.2019.1610085. [Epub ahead of print].
- Marcum ZA, Gellad WF. Medication adherence to multidrug regimens. *Clin Geriatr Med.* 2012;28(2):287–300.
- Maher RL, Hanlon J, Hajjar ER. Clinical consequences of polypharmacy in elderly. *Expert Opin Drug Saf.* 2014;13(1):57–65.
- Whalley Hammell K. Quality of life after spinal cord injury: a meta-synthesis of qualitative findings. *Spinal Cord.* 2007;45(2):124–39.

- 20 Hand BN, Krause JS, Simpson KN. Polypharmacy and adverse drug events among propensity score matched privately insured persons with and without spinal cord injury. *Spinal Cord*. 2018;56(6):591–7.
- 21 Stern S, Merwin E, Holt F. Survival models of community tenure and length of hospital stay for the seriously mentally III: A 10-year perspective. *Health Serv Outcomes Res Methodol*. 2001;2(2):117–35.
- 22 Vrijens B, De Geest S, Hughes DA, Przemyslaw K, Demonceau J, Ruppert T, *et al*. A new taxonomy for describing and defining adherence to medications. *Br J Clin Pharmacol*. 2012;73(5):691–705.
- 23 Canadian Pharmacists Association. Medication management [cited March 15, 2019]. Available from <https://www.pharmacists.ca/education-practice-resources/professional-development/medication-management/>.
- 24 Kripalani S, Henderson LE, Chiu EY, Robertson R, Kolm P, Jacobson TA. Predictors of medication self-management skill in a low-literacy population. *J Gen Intern Med*. 2006;21:852–6.
- 25 MacLaughlin EJ, Raehl CL, Treadway AK, Sterling TL, Zoller DP, Bond CA. Assessing medication adherence in the elderly. *Drugs Aging*. 2005;22(3):231–55.
- 26 Hope CJ, Wu J, Tu W, Young J, Murray MD. Association of medication adherence, knowledge, and skills with emergency department visits by adults 50 years or older with congestive heart failure. *Am J Health Syst Pharm*. 2004;61:2043–9.
- 27 Brown MT, Bussell JK. Medication adherence: WHO cares? *Mayo Clin Proc*. 2011;86(4):304–14.
- 28 Sabaté E. Adherence to Long-Term Therapies: Evidence for Action. Geneva: World Health Organization; 2003.
- 29 Osterberg L, Blaschke T. Adherence to medication. *N Engl J Med*. 2005;353:487–97.
- 30 Heisler M, Bouknight RR, Hayward RA, Smith DM, Kerr EA. The relative importance of physician communication, participatory decision making, and patient understanding in diabetes self-management. *J Gen Intern Med*. 2002;17:243–52.
- 31 Lee W, Noh Y, Kang H, Hong SH. The mediatory role of medication adherence in improving patients' medication experience through patient-physician communication among older hypertensive patients. *Patient Prefer Adherence*. 2017;11:1119–26.
- 32 Lowes R. Patient-centered care for better patient adherence. *Fam Pract Manag*. 1998;5(3):46–57.
- 33 Patton MQ. *Qualitative Research & Evaluation Methods*. Thousand Oaks, CA: Sage; 2002.
- 34 de Casterle B D, Gastmans C, Bryon E, Denier Y. QUAGOL: a guide for qualitative data analysis. *Int J Nurs Stud*. 2012;49(3):360–71.
- 35 Miles MB, Huberman AM, Saldaña J. *Qualitative Data Analysis: A Methods Sourcebook*. Thousand Oaks, CA: Sage; 2014.
- 36 Berben L, Dobbels F, Engberg S, Hill MN, De Geest S. An ecological perspective on medication adherence. *West J Nurs Res*. 2012;34(5):635–53.
- 37 Kenning C, Coventry PA, Gibbons C, Bee P, Fisher L, Bower P. Does patient experience of multimorbidity predict self-management and health outcomes in a prospective study in primary care? *Fam Pract*. 2015;32(3):311–6.
- 38 Guilcher SJ, Craven BC, Lemieux-Charles L, Casciaro T, McColl MA, Jaglal SB. Secondary health conditions and spinal cord injury: an uphill battle in the journey of care. *Disabil Rehabil*. 2013;35(11):894–906.
- 39 McColl MA, Aiken A, McColl A, Sakakibara B, Smith K. Primary care of people with spinal cord injury. *Can Fam Physician*. 2012;58:e626–35.
- 40 Haggerty JL. Ordering the chaos for patients with multimorbidity. *BMJ: Br Med J*. 2012;345:e5915–6.
- 41 Boyd CM, Lucas GM. Patient-centered care for people living with multimorbidity. *Curr Opin HIV AIDS*. 2014;9(4):419–27.
- 42 American Pharmacists Association. Medication adherence. Available from <https://www.pharmacist.com/measuring-adherence>.
- 43 Brar Prayaga R, Jeong EW, Feger E, Noble HK, Kmiec M, Prayaga RS. Improving refill adherence in medicare patients with tailored and interactive mobile text messaging: pilot study. *JMIR Mhealth Uhealth*. 2018;6(1):e30. doi:10.2196/mhealth.8930.
- 44 Grenard JL, Munjas BA, Adams JL, Suttrop M, Maglione M, McGlynn EA, *et al*. Depression and medication adherence in the treatment of chronic diseases in the United States: a meta-analysis. *J Gen Intern Med*. 2011;26(10):1175–82.