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Complete List of Authors:	Moreno, Jhon; McGill University, School of Physical and Occupational Therapy Zidarov, Diana; McGill University, School of Physical and Occupational Therapy Raju, Chandhana; McGill University, School of Physical and Occupational Therapy Boruff, Jill; McGill University, Schulich Library of Science and Engineering Ahmed, Sara; McGill University, School of Physical and Occupational Therapy
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Alexander Moreno[1, 2], Diana Zidarov[1, 2], Chandhana Raju[1, 2], Jill Boruff[3] & Sara Ahmed[1, 2]

[1]Faculty of Medicine, School of Physical and Occupational Therapy, McGill University, CANADA

[2]Center for Interdisciplinary Research in Rehabilitation of Greater Montreal, CANADA

[3]Schulich Library of Science and Engineering, McGill University, CANADA

Address for correspondence:

Alexander Moreno, Ph.D. & Sara Ahmed, Ph.D.

Center for Interdisciplinary Research in Rehabilitation (CRIR) – Constance-Lethbridge Rehabilitation Centre, CIUSSS Centre-Ouest-de-l'Île-de-Montréal, 7005, Maisonneuve Blvd. West, Room 2-335

Email: jhon.moreno@mail.mcgill.ca ; jhon.alexander.moreno@umontreal.ca ; sara.ahmed@mcgill.ca

Institutional addresses and emails:

Alexander Moreno, Ph.D.: Center for Interdisciplinary Research in Rehabilitation (CRIR) – Constance-Lethbridge Rehabilitation Centre, CIUSSS Centre-Ouest-de-l'Île-de-Montréal, 7005, Maisonneuve Blvd. West, Room 2-335. Email: jhon.moreno@mail.mcgill.ca ; jhon.alexander.moreno@umontreal.ca

Diana Zidarov, pht, Ph.D. Faculty of Medicine, School of Physical and Occupational Therapy, McGill University, 3654 Prom. Sir William Osler, Montreal, Quebec, Canada; Center for Interdisciplinary Research in Rehabilitation (CRIR) – Constance-Lethbridge Rehabilitation Centre, CIUSSS Centre-Ouest-de-l'Île-de-Montréal, 7005, Maisonneuve blvd West, Room 2-335 Email: diana.zidarov@mail.mcgill.ca

Chandhana Raju, B.S.: Constance-Lethbridge Rehabilitation Centre, CIUSSS Centre-Ouest-de-l'Île-de-Montréal, 7005, Maisonneuve Blvd. West, Room 2-335. Email: chandhana.raju@mail.mcgill.ca

Jill Boruff, M.L.I.S.: Schulich Library of Science and Engineering, Macdonald-Stewart Library Building 809 Sherbrooke Street West, Montreal, Quebec H3A 0C1. Email: jill.boruff@mcgill.ca

Sara Ahmed, Ph.D.: Center for Interdisciplinary Research in Rehabilitation (CRIR) – Constance-Lethbridge Rehabilitation Centre, CIUSSS Centre-Ouest-de-l'Île-de-Montréal, 7005, Maisonneuve blvd West, Room 2-335. Email: sara.ahmed@mcgill.ca

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Abstract

Introduction: There is fragmented information about the different needs following a spinal cord injury (SCI). The information available comes from different stakeholders, such as individuals with SCI, healthcare professionals, and family caregivers. Expressed SCI needs can be met or unmet, they change along the rehabilitation continuum, and can be different for traumatic and non traumatic SCI. The objective of this scoping study is to evaluate and integrate the needs of individuals with SCI, their family caregivers, and those reported by rehabilitation professionals.

Methods and analysis: The scoping study involves four steps: a) identifying the research question guiding the scoping study, mainly, the most frequent met and unmet needs reported by adults with traumatic and non traumatic SCI, their family caregivers, and their rehabilitation professionals across the continuum of care; b) identifying relevant studies with a search in electronic databases (Ovid Medline, CINAHL, EMBASE, PsycINFO, Cochrane Library, Web of Science, ProQuest Dissertations and Theses); c) charting the data based on categories refined and adjusted with a stakeholder group to make sure that the relevant information will be extracted; d) collating, summarizing, and reporting the results using as analytical frameworks the Maslow's hierarchical model of human needs and the Ferrans et al.'s model of Health-Related Quality of Life (HRQoL), and e) a stakeholder consultation phase to translate findings among potential knowledge users.

Ethics and dissemination: The main concerns related to a SCI needs scoping study are discussed, such as methodological limitations about the type of conclusions that can be drawn and the analytical frameworks for the interpretation of findings. The results of this scoping study will inform best practices for the translation of evidence-based care into clinical practice and the development of new technologies in rehabilitation.

Keywords: Spinal Cord Injury, needs, caregiver, healthcare, scoping study.

Introduction

Spinal Cord Injury (SCI) corresponds to a neurological condition affecting 330 to 400 per 100,000 Canadians living in the community [1]. SCI affects mainly young and middle-aged adults, with men showing the highest prevalence regardless of age group (men-to-women ratio of 4.4:1) [2]. Furthermore, SCI is a high-cost chronic disability [3] involving changes in roles, self-image, body function, social interactions, and family relationships [4].

For individuals with SCI, the injury permanently transforms their lives. Indeed, SCI can result in diverse motor, sensory, and autonomic problems [5]. Mobility impairment (e.g., paraplegia, tetraplegia), bowel and bladder incontinence, loss of sensation, and sexual dysfunction are common following SCI [6]. As a result, individuals with SCI have complex health needs as their condition includes chronic multimorbidity, mainly associated with the development of several secondary health conditions (e.g., pain and pressure ulcers) [6]. In addition, compared to community estimates, higher rates of psychological disorders can be present in 17 to 25% of individuals with SCI [7]. Particularly, between 18-37% of individuals with SCI experience depression [8, 9]. Also, studies regarding long-term outcomes indicate that individuals with SCI have low employment rates 20 years post-injury [10]. A review shows that employment rates following SCI range from 11 to 69% depending on the definition of employment and differences in the study methodology [11]. Thus, SCI has an important functional, psychological, and social impact on individuals that requires an integrated care approach across the continuum from acute care to community living. For instance, a Canadian report by the Rick Hansen Institute stressed the need for lifetime access to rehabilitation healthcare for individuals with SCI [12]. Individuals with SCI require follow-up to address their evolving health needs, including the challenges that represent aging with a disability and the development of SCI-related secondary health conditions.

For families, the unforeseen nature of the injury leads some of the members into an "unexpected career" as family caregivers [13]. As family caregivers normally do not have training for the caregiving tasks (e.g., bathing, dressing, feeding), they can experience role transitions [14], strain [15], isolation [6], burden [16], poor leisure satisfaction [17], reduced ability to become and remain employed [18], and marital disruption [19]. Compared to family caregivers of different neurological conditions, family caregivers of individuals with SCI have experienced more frequent physical distress and present increased odds of coronary heart disease and obesity [20]. Thus, their experience as family caregivers is crucial to understand the needs of individuals with SCI, as they progressively become experts by experience while providing care, supporting and addressing the needs of the care recipient with SCI.

For rehabilitation professionals, understanding the interplay of different factors influencing support mechanisms to assist the transition to home and community after discharge can facilitate social reintegration of the individual with SCI [21]. In fact, rehabilitation professionals have an understanding of the needs and barriers that individuals with SCI can encounter. Their observations are valuable as experts due to their professional roles with good knowledge about the problems that individuals with SCI face [22]. Also, they can directly contribute to the understanding of the rehabilitation process and the pre- and post-discharge challenges during service delivery. For instance, shorter lengths of stay during inpatient rehabilitation can diminish the opportunities to provide information and efficiently train dyads of individuals with SCI and their family caregivers when they return to the community [21]. Thus, the healthcare professional's perspective is necessary when depicting a thorough picture of the barriers to meet the needs of individuals with SCI.

Individuals with SCI and their families, as well as healthcare professionals must work together to effectively meet the diverse post-SCI needs. Their perceptions do not always coincide and therefore all perspectives need to be taken into account. Indeed, there are differences between the views coming

from the clinicians and those of individuals with SCI regarding their treatment [23]. For instance, a study showed that compared to physiotherapists, some individuals with SCI have unrealistically high expectations about walking one year post-injury [24]. Another study showed that when the perspectives of individuals with SCI are acknowledged during rehabilitation, they become more committed to therapy, they express more confidence in their treating clinicians, and have better satisfaction and outcomes [25]. The challenge is in understanding the evolution of these needs as they change over time. The literature on SCI needs indicates that in the first year post-discharge, the fulfillment of critical needs (e.g., housing, transportation) is below 60% [26], while the long-term care needed is higher than the care received for information and psychosocial care needs [27]. Further, there are differences in needs between individuals with traumatic and non-traumatic SCI. Compared to individuals with non traumatic SCI (>70%), individuals with traumatic SCI (>85%) report more expressed needs on equipment and technical aids, short-distance transportation, accessible housing, general healthcare, and SCI-specialized healthcare [28]. In addition, individuals with non traumatic SCI report more unmet needs in accessible housing, job training, and peer support [29]. Finally, fully addressing the needs of individuals' with SCI must include evaluating and targeting the needs of family caregivers. Family caregivers of individuals with SCI report health information needs as the most important and emotional support needs as those most often unmet [30]. Family caregivers are an important resource in the treatment of individuals with SCI considering that the quality of the care they provide matches or exceeds the quality of professional care [31]. But unmet caregiver needs may prevent optimal care and negatively affect the health of both the care recipients and their own. From a clinical perspective, understanding the needs of individuals with SCI, knowing the person, and working with the family can be beneficial to guide their healthcare and improve outcomes [32]. As unmet needs have a direct relationship with diminished quality of life [28], it is mandatory to understand them and to find ways to meet them. In consequence, obtaining a comprehensive picture of needs by integrating the different perspectives of professionals, family caregivers, and individuals with SCI is paramount.

Therefore, previous studies have evaluated SCI needs independently considering factors including needs at different points of the rehabilitation continuum (e.g., inpatient, outpatient, and community) and with different types of SCI (e.g., traumatic versus non traumatic SCI, complete versus incomplete), from the perspective of individuals with SCI, family caregivers, and healthcare professionals. Further, studies have mainly considered SCI needs form a health services perspective rather than from a patient-centered perspective that accounts for areas that influence needs outside of the health system. To our knowledge there are no previous studies that have evaluated the variations in factors and synthesising these needs together from a patient-centered perspective. With fragmented information, it remains difficult for patients, family caregivers, health professionals, and researchers to understand the current gaps in SCI care and the most efficient ways to deliver care that are most likely to address unmet needs.

The objective of this study is to review the literature on SCI needs using a scoping study approach given the diffuse literature on SCI needs. Scoping studies allow for an appraisal of the literature and have four objectives [33]: a) to examine the extent, range, and nature of the research activity, b) to determine the value of conducting a systematic review, c) to summarize and disseminate research findings, and d) to identify gaps in the literature. This methodological strategy was chosen because compared to systematic reviews, scoping studies address broader topics and questions where different study designs are used, they intend to rapidly map the key concepts of a research area, and they encompass a comprehensive coverage of the literature (breadth more than in-depth). This scoping study will provide broad understanding and synthesis of SCI needs as reported by different stakeholders, for traumatic and non-traumatic SCI, across the care continuum. This scoping study will help us to identify unexplored areas of SCI needs and to provide recommendations to improve the quality of health services, to inform the development of new interventions to address unmet needs.

Theoretical frameworks

SCI needs will be synthesised based on two guiding theoretical frameworks: a) the conceptual framework of Maslow's *hierarchy model of needs* coming from humanistic psychology [34] and the Ferrans and colleagues' model of Health-Related Quality of Life (HRQoL), which is a modified version of the Wilson and Cleary model of HRQoL [35]. Both the Maslow's model and the Ferrans et al.'s model are informative and appropriate to frame SCI needs taking into account the perspectives of different stakeholders.

The definition of needs has been variable across published studies. Some of them define needs as the discrepancies between what is desired or optimal based on a guideline, and what is actually occurring [36], a circumstance requiring a course of action [37], or services that are necessary to support individual's community living [28]. For the current scoping study, a broader definition of needs corresponds to a lack of something that is essential to a person's existence or well-being, according to Maslow's hierarchical model [38]. In his groundbreaking theory of motivation, Maslow describes human needs as being hierarchical. Figure 1 depicts the pyramidal representation of human needs. As described in his theory, human needs can be classified in five levels: a) physiological needs, b) safety and security needs, c) belonging and love needs, d) esteem needs, and e) self-actualization needs. In healthcare, the hierarchical model of needs has been applied to nursing [39], geriatric care [40], intensive care [41], palliative care [42], disability and rehabilitation [43], as well as to specific conditions such as dementia [44], type 1 diabetes [45], addiction [46], homeless adults with serious mental illness [47], and dissociative and conversion disorders [48]. Although some of these needs cannot be provided by the health system, the use of this framework has been useful to prioritize, conceptualize and understand needs, to develop a more humanistic approach to successful healthcare, to support person-centered care planning, and to redefine, change and improve the culture of care.

Given that a SCI impacts all domains of the person's life (physical, social, psychological) needs are not only related to the characteristics of the individual but also the environment the person lives in. Therefore the Ferrans et al's model of HRQoL complements Maslow's model as it provides a guide for understanding characteristics of the individual (that are mainly encompassed in the hierarchy model of needs), but also the environmental component (e.g., physical and social environment), as well as health-related domains that influence general health perceptions and quality of life (e.g., symptoms, function, and participation) that need to be addressed when making evidence-based recommendations regarding unmet SCI needs [49]. Thus, both theoretical models will provide an understanding of the dynamics between the motivational aspects associated with SCI-needs (Maslow) and the environmental influences on the HRQoL of individuals with SCI (Ferrans et al), given that unmet needs have a direct relationship with diminished quality of life [28].

Figure 1. Maslow's hierarchy model of human needs

Insert Figure 1 here

In summary, as studies about SCI needs are conducted in different points of the rehabilitation continuum (e.g., inpatient, outpatient, and community) and with different types of injuries (e.g., traumatic versus non traumatic SCI, complete versus incomplete), a scoping study approach integrating the different perspectives of healthcare professionals, family caregivers, and individuals with SCI, guided by the Maslow and the Ferrans et al's models can help to depict a comprehensive picture of their needs. SCI needs are ongoing and they change in the rehabilitation continuum over the years [50]. In the very stressful period of the acute phase, SCI needs are not the same as the situation is not immediately assimilated following the injury, whereas outside the rehabilitation center SCI needs

change depending on the path that individuals follow [51]. This integrative approach will help to identify research gaps regarding SCI needs across the continuum of care and to holistically understand the met and unmet needs to improve healthcare (see figure 2).

Figure 2. Integrative approach towards SCI needs

Insert Figure 2 here

Methods

The current scoping study will use the methodology described by Arksey and O'Malley (2005) [33] .

Step 1. Identifying the research question

The research question guiding the current scoping study is "Which are the most frequent met and unmet needs (e.g., information needs, home support needs, personal care needs, respite needs, psychological support needs, educational needs, employment needs, sexuality needs, technological needs, telerehabilitation needs, spiritual needs, among others) reported by adults with traumatic and non traumatic SCI, their family caregivers, and their rehabilitation professionals across the continuum of care?"

Specifically, the current scoping study has four objectives:

1. To synthesize the needs of individuals with SCI as perceived by themselves, their family caregivers, and their rehabilitation professionals according to the categories of the hierarchy of human needs and the Ferrans et al.'s model of HRQoL.
2. To classify needs as met and unmet.

3. To explore the evolution of met/unmet needs across the continuum of care.
4. To provide recommendations to improve SCI care.

Step 2. Identifying eligible studies

We will search published articles with the following inclusion criteria: a) publications from all health professions, b) describing different needs in both traumatic and non traumatic SCI, c) participants with 18 years of age and older, d) including acute to chronic injuries, e) regardless of year of publication, f) qualitative and quantitative studies, g) available in English language, and f) grey literature. We will exclude: a) conference abstracts, b) articles published in other languages, and c) studies addressing paediatric populations.

Search strategy and information sources

A health science librarian (JB) developed the search strategy for Ovid Medline (Table 1) and had it peer reviewed by another librarian per the PRESS standard [52]. This search strategy will be adapted for subsequent databases. The following databases will be searched with no date or language limits applied: Ovid Medline®, CINAHL, EMBASE, PsycINFO, Cochrane Library, Web of Science, ProQuest Dissertations and Theses.

Grey literature will be searched on SCI websites, scientific and professional associations, and also using search engines on the Internet (e.g., Google and Yahoo). When using search engines, we will retain the first 50 results for the analysis given the amount of information available.

Table 1. Search strategy for Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to present

1	exp Spinal Cord Injuries/
2	spinal cord injur*.tw,kf.
3	exp Paraplegia/
4	Quadriplegia/
5	tetraplegia.tw,kf.
6	paraplegia.tw,kf.
7	Quadriplegia.tw,kf.
8	spinal column injur*.tw,kf.
9	central cord injur*.tw,kf.
10	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9
11	((met or unmet or expressed) adj3 (need or needs)).tw,kf.
12	Needs Assessment/
13	"Health Services Needs and Demand"/
14	Patient Preference/
15	Patient Satisfaction/
16	(sexual* adj2 (concern* or satisfaction or need or needs)).tw,kf.
17	((caregiver* or famil* or spouse* or person* or patient* or client* or individual* or user* or research) adj3 (priorities or expectation* or preference* or perspective*)).tw,kf.
18	((self-actualization or self-esteem or esteem or spiritual or belonging or love or physiological or security or caregiver* or famil* or spouse* or transportation or support or social or economic or health or life or telerehabilitation or rehabilitation or rehabilitative or information or economic or emotional or community or home or personal care or respite or psychological or instrumental or safety or health care or healthcare or educational or employment or leisure or housing or technological) adj3 (need or needs)).tw,kf.
19	11 or 12 or 13 or 14 or 15 or 16 or 17 or 18
20	self concept/ or self efficacy/
21	(satisfaction or needs).tw,kf.
22	20 and 21
23	19 or 22
24	10 and 23

Step 3: Study selection

In the first step, a reference management software (EndNote X7) will be used to merge the results and remove the duplicates before screening the abstracts. Later, a data extraction form will be developed by the research team to screen the abstracts based on the eligibility criteria described in step 2. Two independent reviewers will conduct the selection of abstracts starting with a pilot phase involving the

examination of the first 20 titles and abstracts to screen and decide the retention of the abstract based on the inclusion criteria. The results of the independent ratings will be recorded separately using the data extraction form. Inter-rater agreement will be assessed using the kappa statistic [53]. Inter-rater agreement below 75% will lead to a revision and clarification of the eligibility criteria. The process will be repeated until an agreement of 75% will be reached, which is evidence of excellent agreement. This is important as it is recommended that discussions are being held regarding the challenges and uncertainties related to study selection and to refine the search strategy as needed [54]. Finally, all eligible studies and those classified as unclear (i.e., requiring further information to make a final decision regarding their retention) will be independently reviewed as full-text articles. Inter-rater agreement will be re-assessed using the kappa statistic [53] on a random sample of 10 publications. Disagreements at this stage will be resolved by consensus. In case of persistent disagreement, a third reviewer will be consulted to determine the final inclusion.

Step 4. Data extraction process

The data extracted in the previous step will include the information corresponding to author(s), year of publication, country of origin and context (where the study was conducted), status of publication (e.g., published or grey literature), journal, aims/purpose, study population (individuals with SCI, family caregivers, rehabilitation professionals) and sample size (if applicable), SCI type (traumatic and non traumatic), level(s) of care (acute, primary care, community), time since SCI, methodology/methods (study design, measures), key findings that relate to the scoping study question/s (in terms of met and unmet specific categories of needs). At this stage, two independent reviewers will extract the information based on the first 10 publications. Also, during the charting of the information, the reviewers will meet following the extraction of the first 10 studies to make sure that the data extraction follows consistently the purpose of the study. A meeting to evaluate the consistency of the information

extracted will allow the reviewers to identify inconsistencies and make decisions regarding the best way to deal with ambiguity.

An iterative process consisting of inter-reviewer discussions held at the beginning, in the middle and at the end of the extraction will lead to a consensus regarding the best way to extract the data. When disagreements persist, a third independent reviewer will be consulted.

Step 5. Data synthesis

This phase involves collating, summarizing, and reporting the results. Compared to systematic reviews, scoping studies present a narrative account of a potentially large body of material [33]. Thus, guided by the previous theoretical frameworks, we intend to identify a descriptive numerical summary (e.g., characteristics of included studies, types of study design, characteristics of the study population, geographical location) and emerging themes (deductive thematic analysis) [54]. Using as an analytical framework the Maslow's hierarchical model of human needs, we will extract the main themes corresponding to the five categories of human needs and classify them as described by professionals, family caregivers, and individuals with SCI. When available, unmet SCI needs will be classified based on the Ferrans et al.'s model of HRQoL as characteristics of the individual and characteristics of the environment, and their relationship with other components (e.g., biological function, symptoms, functional status, general health perceptions, and overall quality of life). Following the thematic analysis, special considerations regarding the implications for research, policy and practice will be presented.

Step 6: Stakeholder consultation

The objective of this stage is to start translating knowledge into practice by disseminating results among potential knowledge users. This consultation will be done at the beginning of the process

(requesting feedback to refine the research question and make sure that the research team is not missing useful information), during the study (validate the data extraction, decide the best way to align the information with stakeholders' needs) and when preliminary or final results are available (knowledge mobilisation). For the current scoping study, relevant stakeholders include support groups of individuals with SCI and their family caregivers, clinicians, and decision-makers. The meetings will be organized either in a face-to-face format or using videoconference to allow broader participation, giving equal representation to the different groups.

Discussion

The current scoping study will answer the question about the most frequent met and unmet needs reported by adults with traumatic and non traumatic SCI, their family caregivers, and their rehabilitation professionals across the continuum of care. The results of the current scoping study could have implications from different viewpoints: a) rehabilitation can be informed from the synthesis of SCI needs because clinicians can become more sensitive as they increase awareness about the complexity of SCI expressed and unmet needs across the continuum of care, b) service provision could be modified from gaining understanding about the gap between unmet and expressed needs, c) the view of rehabilitation as a changing process with evolving needs in different phases of care can help clinicians to understand and modify their practice when considering SCI needs as dynamic in different stages of care, d) the conception of new studies can be informed based on our comprehensive picture of SCI needs as it will suggest priorities in the research agenda, e) the development of new interventions could benefit from our conclusions as they will provide information to help to make informed decisions to address the most important unmet needs as outcomes, and f) policy makers could benefit from these results as they will be able to implement modifications to existent programs to adjust to the

complexities of the interactions among different stakeholders involved in the provision of services to increase SCI needs satisfaction.

Scoping studies have some methodological limitations that include the fact that the quality of the evidence is not appraised. Compared to systematic reviews where the quality appraisal and the relative weight of evidence in favour or against a specific intervention is very important, scoping studies are descriptive and narrative [33]. However, scoping studies provide valid specific research questions needing a systematic review through a careful process of scrutinizing evidence coming from different methodologies and study designs. Also, scoping studies are not a short summary of many articles and, as such, they use frameworks or themes to articulate their findings [54]. For the current scoping study, the theoretical frameworks guiding the analysis of the information have been carefully chosen and weighted against other competing models. However, we are aware that the findings could be interpreted using alternative analytical frameworks.

In conclusion, this study protocol presents the rationale and methodology for a scoping study on SCI needs. Through a rigorous and transparent method, engaging individuals with SCI, caregivers, and health professionals at each step, it will provide a framework to understand the most frequent met and unmet needs as reported by adults with traumatic and non traumatic SCI, their family caregivers, and their rehabilitation professionals across the continuum of care.

a. Contributorship statement: AM (preliminary literature review, drafting of the manuscript, integrations of the edits in the different versions, and manuscript submission), DZ (edits and feedback), CJ (edits and feedback), JB (database search), SA (edits and feedback).

b. Competing interests: None

c. Funding: Lindsay foundation (INSPIRE). Fonds de la recherche du Québec-Santé (FRQS). Networks of Centres of Excellence of Canada (AGE-WELL NCE).

d. Data sharing statement: N/A

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Figure 1. Maslow's hierarchy model of human needs

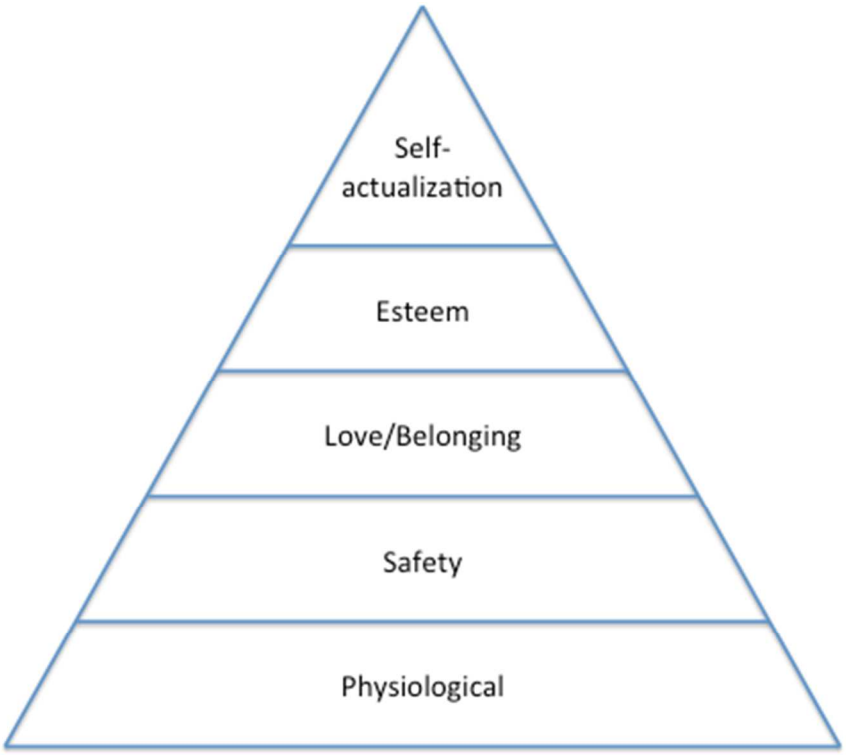

Figure 2. Integrative approach towards SCI needs

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Integrating the perspectives of individuals with spinal cord injuries, their family caregivers, and healthcare professionals across the continuum of care: protocol for a scoping study on SCI needs

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Integrating the perspectives of individuals with spinal cord injuries, their family caregivers, and healthcare professionals across the continuum of care: protocol for a scoping study on SCI needs

Alexander Moreno[1, 2], Diana Zidarov[1, 2], Chandhana Raju[1, 2], Jill Boruff[3] & Sara Ahmed[1, 2]

[1]Faculty of Medicine, School of Physical and Occupational Therapy, McGill University, CANADA

[2]Center for Interdisciplinary Research in Rehabilitation of Greater Montreal, CANADA

[3]Schulich Library of Science and Engineering, McGill University, CANADA

Address for correspondence:

Sara Ahmed, Ph.D.

Center for Interdisciplinary Research in Rehabilitation (CRIR) – Constance-Lethbridge Rehabilitation Centre, CIUSSS Centre-Ouest-de-l'Île-de-Montréal, 7005, Maisonneuve Blvd. West, Room 2-335

Email: sara.ahmed@mcgill.ca

Institutional addresses and emails:

Alexander Moreno, Ph.D.: Faculté des sciences humaines, Département de sexologie, Université du Québec à Montréal (UQÀM), C.P. 8888, Succ. Centre-Ville, Montréal, Québec, Canada, H3C-3P8. Center for Interdisciplinary Research in Rehabilitation (CRIR) – Constance-Lethbridge Rehabilitation Centre, CIUSSS Centre-Ouest-de-l'Île-de-Montréal, 7005, Maisonneuve Blvd. West, Room 2-335. Email: moreno.jhon_alexander@uqam.ca ; jhon.moreno@mail.mcgill.ca

Diana Zidarov, pht, Ph.D. Faculty of Medicine, School of Physical and Occupational Therapy, McGill University, 3654 Prom. Sir William Osler, Montreal, Quebec, Canada; Center for Interdisciplinary Research in Rehabilitation (CRIR) – Constance-Lethbridge Rehabilitation Centre, CIUSSS Centre-Ouest-de-l'Île-de-Montréal, 7005, Maisonneuve blvd West, Room 2-335 Email: diana.zidarov@mail.mcgill.ca

Chandhana Raju, B.S.: Constance-Lethbridge Rehabilitation Centre, CIUSSS Centre-Ouest-de-l'Île-de-Montréal, 7005, Maisonneuve Blvd. West, Room 2-335. Email: chandhana.raju@mail.mcgill.ca

Jill Boruff, M.L.I.S.: Schulich Library of Science and Engineering, Macdonald-Stewart Library Building 809 Sherbrooke Street West, Montreal, Quebec H3A 0C1. Email: jill.boruff@mcgill.ca

Sara Ahmed, Ph.D.: Center for Interdisciplinary Research in Rehabilitation (CRIR) – Constance-Lethbridge Rehabilitation Centre, CIUSSS Centre-Ouest-de-l'Île-de-Montréal, Institut de réadaptation Gingras-Lindsay-de-Montréal du CIUSSS du Centre-Est-de-l'Ile-de-Montréal, 7005, Maisonneuve blvd West, Room 2-335; Faculty of Medicine, School of Physical & Occupational Therapy, McGill

University. 3654 Prom Sir-William-Osler, Montreal, QC, Canada, H3G 1Y5; McGill University Health Center, Clinical Epidemiology, 687 Pine Ave W, Montreal, QC, Canada, H3A 1A1

Email: sara.ahmed@mcgill.ca

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Abstract

Introduction: There is fragmented information about the different needs following a spinal cord injury (SCI). Expressed SCI needs can be met or unmet, they change along the rehabilitation continuum (e.g., acute, rehabilitation, and reintegration into the community), and can be different for traumatic and non traumatic SCI. The general objective of this scoping study is to evaluate and integrate the needs of individuals with traumatic and non traumatic SCI, their family caregivers, and those reported by rehabilitation professionals across the continuum from the time of rehabilitation admission to community reintegration. The specific objectives are to: a) synthesize the needs of individuals with SCI as perceived by themselves, their family caregivers, and rehabilitation professionals using two theoretical models, b) classify needs as met and unmet, c) explore the evolution of met/unmet needs across the continuum of care, and d) provide recommendations to improve SCI care.

Methods and analysis: a) identifying the most frequent met and unmet needs reported by adults with traumatic and non traumatic SCI, their family caregivers, and their rehabilitation professionals across the continuum of care; b) identifying relevant studies with a search in electronic databases; c) charting the data based on categories refined and adjusted with a stakeholder group; d) collating, summarizing, and reporting the results two analytical frameworks (Maslow's hierarchical model of human needs and the Ferrans et al.'s model of Health-Related Quality of Life), and e) a stakeholder consultation phase.

Ethics and dissemination: The results of this scoping study will allow understanding SCI needs across the continuum of care from the perspective of different stakeholders. An integrated master report combining the needs of individuals with SCI from the perspectives of different stakeholders across the continuum of care will follow the consultation meetings.

Keywords: Spinal Cord Injury, needs, caregiver, healthcare, scoping study.

Introduction

Spinal Cord Injury (SCI) corresponds to a neurological condition affecting 330 to 400 per 100,000 Canadians living in the community [1]. According to provincial data, traumatic SCI affects mainly young and middle-aged adults, with men showing the highest prevalence regardless of age group (men-to-women ratio of 4.4:1) [2]. Traumatic SCI is concentrated in younger populations, while non traumatic SCI is condensed in older age groups [3]. In addition, Canadian estimates indicate that compared to non traumatic SCI (49%), the prevalence is higher for traumatic SCI (51%) [3]. Furthermore, SCI is a high-cost chronic disability [4] involving changes in roles, self-image, body function, social interactions, and family relationships [5].

For individuals with SCI, the injury permanently transforms their lives. Indeed, SCI can result in diverse motor, sensory, and autonomic problems [6]. Mobility impairment (e.g., paraplegia, tetraplegia), bowel and bladder incontinence, loss of sensation, and sexual dysfunction are common following SCI [7]. As a result, individuals with SCI have complex health needs as their condition includes chronic multimorbidity, mainly associated with the development of several secondary health conditions (e.g., pain and pressure ulcers) [7]. In addition, compared to community estimates, higher rates of psychological disorders can be present in 17 to 25% of individuals with SCI [8]. Particularly, between 18-37% of individuals with SCI experience depression [9 10].

Also, studies regarding long-term outcomes indicate that individuals with SCI have low employment rates 20 years post-injury [11]. A review shows that employment rates following SCI range from 11 to 69% depending on the definition of employment and differences in the study methodology [12]. Thus, SCI has an important functional, psychological, and social impact on individuals that requires an integrated care approach across the continuum from acute care to community living. For instance,

Craven et al. (2012) stressed the need for lifetime access to rehabilitation healthcare for individuals with SCI [13]. Individuals with SCI require follow-up to address their evolving health needs, including the challenges that represent aging with a disability and the development of SCI-related secondary health conditions.

For families, the unforeseen nature of the injury leads some of the members into an "unexpected career" as family caregivers [14]. As family caregivers normally do not have training for the caregiving tasks (e.g., bathing, dressing, feeding), they can experience role transitions [15], strain [16], isolation [7], burden [17], poor leisure satisfaction [18], reduced ability to become and remain employed [19], and marital disruption [20].

Different perspectives in SCI needs

Individuals with SCI and their families, as well as healthcare professionals must work together to effectively meet the diverse post-SCI needs [21]. For rehabilitation professionals, understanding the interplay of different factors influencing support mechanisms to assist the transition to home and community after discharge can facilitate social reintegration of the individual with SCI [22]. In fact, rehabilitation professionals have an understanding of the needs and barriers that individuals with SCI can encounter. Their observations are valuable as experts due to their professional roles with good knowledge about the problems that individuals with SCI face [23]. Also, they can directly contribute to the understanding of the rehabilitation process and the pre- and post-discharge challenges during service delivery. For instance, shorter lengths of stay during inpatient rehabilitation can diminish the opportunities to provide information and efficiently train dyads of individuals with SCI and their family caregivers when they return to the community [22]. Thus, the healthcare professional's perspective is necessary when depicting a thorough picture of the barriers to meet the needs of individuals with SCI. For instance, a study showed that compared to physiotherapists, some individuals with SCI have unrealistically high expectations about walking one year post-injury [24]. Another study showed that

when the perspectives of individuals with SCI are acknowledged during rehabilitation, they become more committed to therapy, they express more confidence in their treating clinicians, and have better satisfaction and outcomes [25].

Compared to family caregivers of different neurological conditions, family caregivers of individuals with SCI have experienced more frequent physical distress and present increased odds of coronary heart disease and obesity [26]. Thus, their experience as family caregivers is crucial to understand the needs of individuals with SCI, as they progressively become experts by experience while providing care, supporting and addressing the needs of the care recipient with SCI. Family caregivers are an important resource in the treatment of individuals with SCI considering that the quality of the care they provide matches or exceeds the quality of professional care [27]. But unmet caregiver needs may prevent optimal care and negatively affect the health of both the care recipients and their own. From a clinical perspective, understanding the needs of individuals with SCI, knowing the person, and working with the family can be beneficial to guide their healthcare and improve outcomes [28]. As unmet needs have a direct relationship with diminished quality of life [29], it is mandatory to understand them and to find ways to meet them. In consequence, obtaining a comprehensive picture of needs by integrating the different perspectives of professionals, family caregivers, and individuals with SCI is paramount.

Changing needs in the rehabilitation continuum

The challenge is in understanding the evolution of these needs as they change over time. The literature on SCI needs indicates that in the first year post-discharge, the fulfillment of critical needs (e.g., housing, transportation) is below 60% [30], while the long-term care needed is higher than the care received for information and psychosocial care needs [31]. Further, there are differences in needs between individuals with traumatic and non-traumatic SCI. Compared to individuals with non traumatic SCI (>70%), individuals with traumatic SCI (>85%) report more expressed needs on equipment and

technical aids, short-distance transportation, accessible housing, general healthcare, and SCI-specialized healthcare [29]. In addition, individuals with non traumatic SCI report more unmet needs in accessible housing, job training, and peer support [32]. Finally, fully addressing the needs of individuals' with SCI must include evaluating and targeting the needs of family caregivers. Family caregivers of individuals with SCI report health information needs as the most important and emotional support needs as those most often unmet [33]. Among the health and social consequences of unmet needs, individuals with SCI can present higher rates of multimordidity [7 34], dissatisfaction with their lives, high rates of psychological problems [9], poor quality of life [29] and poor long-term integration into the community [30]. Also, unmet needs lead their family caregivers to invest more hours in their care [27].

Gaps in understanding met and unmet needs

Previous studies have evaluated SCI needs separately at different points of the rehabilitation continuum (e.g., inpatient, outpatient, and community) and with different types of SCI (e.g., traumatic versus non traumatic SCI, complete versus incomplete), from the perspective of individuals with SCI, family caregivers, and healthcare professionals. Further, studies have mainly considered SCI needs from a health services perspective rather than from a patient-centered perspective that accounts for areas that influence needs outside of the health system. To our knowledge there are no previous studies that have evaluated the variations in factors and synthesising these needs together from a patient-centered perspective. With fragmented information, it remains difficult for patients, family caregivers, health professionals, and researchers to understand the current gaps in SCI care and the most efficient ways to deliver care that are most likely to address unmet needs.

The objective of this study is to review the literature on SCI needs using a scoping study approach given the diffuse literature on SCI needs. Scoping studies allow for an appraisal of the literature and have four objectives [35]: a) to examine the extent, range, and nature of the research activity, b) to

determine the value of conducting a systematic review, c) to summarize and disseminate research findings, and d) to identify gaps in the literature. This methodological strategy was chosen because compared to systematic reviews, scoping studies address broader topics and questions where different study designs are used, they intend to rapidly map the key concepts of a research area, and they encompass a comprehensive coverage of the literature (breadth more than in-depth). This scoping study will provide broad understanding and synthesis of SCI needs as reported by different stakeholders, for traumatic and non-traumatic SCI, across the care continuum. This scoping study will help us to identify unexplored areas of SCI needs and to provide recommendations to improve the quality of health services, to inform the development of new interventions to address unmet needs.

Theoretical frameworks to guide the evaluation of unmet needs

SCI needs will be synthesised based on two guiding theoretical frameworks: a) the conceptual framework of Maslow's *hierarchy model of needs* coming from humanistic psychology [36] and the Ferrans et al.'s model of Health-Related Quality of Life (HRQoL), which is a modified version of the Wilson and Cleary model of HRQoL [37]. Both the Maslow's model and the Ferrans et al.'s model are informative and appropriate to frame SCI needs taking into account the perspectives of different stakeholders.

The definition of needs has been variable across published studies. Some of them define needs as the discrepancies between what is desired or optimal based on a guideline, and what is actually occurring [38], a circumstance requiring a course of action [39], or services that are necessary to support individual's community living [29]. For the current scoping study, a broader definition of needs corresponds to a lack of something that is essential to a person's existence or well-being, according to Maslow's hierarchical model [40]. In his groundbreaking theory of motivation, Maslow describes human needs as being hierarchical. Figure 1 depicts the pyramidal representation of human needs. As described in his theory,

human needs can be classified in five levels: a) physiological needs, b) safety and security needs, c) belonging and love needs, d) esteem needs, and e) self-actualization needs. In healthcare, the hierarchical model of needs has been applied to nursing [41], geriatric care [42], intensive care [43], palliative care [44], disability and rehabilitation [45], as well as to specific conditions such as dementia [46], type 1 diabetes [47], addiction [48], homeless adults with serious mental illness [49], and dissociative and conversion disorders [50]. Although some of these needs cannot be provided by the health system, the use of this framework has been useful to prioritize, conceptualize and understand needs, to develop a more humanistic approach to successful healthcare, to support person-centered care planning, and to redefine, change and improve the culture of care.

Given that a SCI impacts all domains of the person's life (physical, social, psychological), needs are not only related to the characteristics of the individual but also the environment the person lives in. Therefore the Ferrans et al's model of HRQoL complements Maslow's model as it provides a guide for understanding characteristics of the individual (that are mainly encompassed in the hierarchy model of needs), but also the environmental component (e.g., physical and social environment), as well as health-related domains that influence general health perceptions and quality of life (e.g., symptoms, function, and participation) that need to be addressed when making evidence-based recommendations regarding unmet SCI needs [51]. Thus, both theoretical models will provide an understanding of the dynamics between the motivational aspects associated with SCI-needs (Maslow) and the environmental influences on the HRQoL of individuals with SCI (Ferrans et al.), given that unmet needs have a direct relationship with diminished quality of life [29].

Figure 1. Maslow's hierarchy model of human needs

Insert Figure 1 here

In summary, as studies about SCI needs are conducted in different points of the rehabilitation continuum (e.g., inpatient, outpatient, and community) and with different types of injuries (e.g., traumatic versus non traumatic SCI, complete versus incomplete), a scoping study approach integrating the different perspectives of healthcare professionals, family caregivers, and individuals with SCI, guided by the Maslow and the Ferrans et al's models can help to depict a comprehensive picture of their needs. SCI needs are ongoing and they change in the rehabilitation continuum over the years [52]. In the very stressful period of the acute phase, SCI needs are not the same because both the families and individuals with SCI need time to adjust to their new reality following the injury, whereas outside the rehabilitation center SCI needs change depending on the path that individuals follow [53]. This scoping study will help to identify research gaps regarding SCI needs across the continuum of care and to holistically understand the met and unmet needs to improve healthcare with an integrative approach including different perspectives (see figure 2).

Figure 2. Integrative approach towards SCI needs

Insert Figure 2 here

Methods

The current scoping study will use the methodology described by Arksey and O'Malley (2005) [35] .

Step 1. Identifying the research question

The research question guiding the current scoping study is "Which are the most frequent met and unmet needs (e.g., information needs, home support needs, personal care needs, respite needs, psychological support needs, educational needs, employment needs, sexuality needs, technological needs, telerehabilitation needs, spiritual needs, among others) reported by adults with traumatic and non traumatic SCI, their family caregivers, and their rehabilitation professionals across the continuum of care?"

Specifically, the current scoping study has four objectives:

1. To synthesize the needs of individuals with SCI as perceived by themselves, their family caregivers, and their rehabilitation professionals according to the categories of the hierarchy of human needs and the Ferrans et al.'s model of HRQoL.
2. To classify needs as met and unmet.
3. To explore the evolution of met/unmet needs across the continuum of care, from the time of rehabilitation admission to the community integration.
4. To provide recommendations to improve SCI care.

Step 2. Identifying eligible studies

We will search published articles with the following inclusion criteria: a) publications from all health professions, b) describing different needs in both traumatic and non traumatic SCI, c) participants with 18 years of age and older, d) from acute to chronic injuries, e) the timeframe of publication will be limited to the last 20 years (1997 to 2017), f) qualitative, quantitative studies, and case reports, g) available in English language, and h) grey literature defined as any documentary material that is non commercially published such as technical reports, thesis' repositories, materials produced by associations and the industry, government documents, and working papers [54]. We will exclude: a)

conference abstracts, b) articles published in other languages, and c) studies addressing paediatric populations.

Search strategy and information sources

A health science librarian (JB) developed the search strategy for Ovid Medline (Table 1) and had it peer reviewed by another librarian per the PRESS standard [55]. As health system issues often change with models of care delivery, the economic climate, and the environment, we have decided to narrow the scope to the past 20 years (1997 to present). This search strategy will be adapted for subsequent databases. The following databases will be searched with no date or language limits applied: Ovid Medline®, CINAHL, EMBASE, PsycINFO, Cochrane Library, Web of Science, ProQuest Dissertations and Theses. We will do hand searches of the reference lists of the selected articles to ensure that we have not missed any relevant information.

Grey literature will be searched on SCI websites, scientific and professional associations, and also using search engines on the Internet (e.g., Google and Yahoo). When using search engines, we will retain the first 50 results for the analysis given the amount of information available.

Table 1. Search strategy for Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1997 to present

1	exp Spinal Cord Injuries/
2	spinal cord injur*.tw,kf.
3	exp Paraplegia/
4	Quadriplegia/
5	tetraplegia.tw,kf.
6	paraplegia.tw,kf.
7	Quadriplegia.tw,kf.

8	spinal column injur*.tw,kf.
9	central cord injur*.tw,kf.
10	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9
11	((met or unmet or expressed) adj3 (need or needs)).tw,kf.
12	Needs Assessment/
13	"Health Services Needs and Demand"/
14	Patient Preference/
15	Patient Satisfaction/
16	(sexual* adj2 (concern* or satisfaction or need or needs)).tw,kf.
17	((caregiver* or famil* or spouse* or person* or patient* or client* or individual* or user* or research) adj3 (priorities or expectation* or preference* or perspective*)).tw,kf.
18	((self-actualization or self-esteem or esteem or spiritual or belonging or love or physiological or security or caregiver* or famil* or spouse* or transportation or support or social or economic or health or life or telerehabilitation or rehabilitation or rehabilitative or information or economic or emotional or community or home or personal care or respite or psychological or instrumental or safety or health care or healthcare or educational or employment or leisure or housing or technological) adj3 (need or needs)).tw,kf.
19	11 or 12 or 13 or 14 or 15 or 16 or 17 or 18
20	self concept/ or self efficacy/
21	(satisfaction or needs).tw,kf.
22	20 and 21
23	19 or 22
24	10 and 23
25	limit 24 to yr="1997 -Current"

Step 3: Study selection

In the first step, a reference management software (EndNote X7) will be used to merge the results and remove the duplicates before screening the abstracts. Later, a data extraction form will be developed by the research team to screen the abstracts based on the eligibility criteria described in step 2. Two independent reviewers will conduct the selection of abstracts starting with a pilot phase involving the examination of the first 20 titles and abstracts to screen and decide the retention of the abstract based on the inclusion criteria. The results of the independent ratings will be recorded separately using the data extraction form. Inter-rater agreement will be assessed using the kappa statistic [56]. Inter-rater agreement below 75% will lead to a revision and clarification of the eligibility criteria. The process will

be repeated until an agreement of 75% will be reached, which is evidence of excellent agreement. This is important as it is recommended that discussions are being held regarding the challenges and uncertainties related to study selection and to refine the search strategy as needed [57]. Finally, all eligible studies and those classified as unclear (i.e., requiring further information to make a final decision regarding their retention) will be independently reviewed as full-text articles. Inter-rater agreement will be re-assessed using the kappa statistic [56] on a random sample of 10 publications. Disagreements at this stage will be resolved by consensus. In case of persistent disagreement, a third reviewer will be consulted to determine the final inclusion.

Step 4. Data extraction process

The data extracted in the previous step will include the information corresponding to author(s), year of publication, country of origin and context (where the study was conducted), status of publication (e.g., published or grey literature), journal, aims/purpose, study population (individuals with SCI, family caregivers, rehabilitation professionals) and sample size (if applicable), SCI type (traumatic and non traumatic), level(s) of care (acute, primary care, community), time since SCI, methodology/methods (study design, measures), key findings that relate to the scoping study question/s (in terms of met and unmet specific categories of needs). At this stage, two independent reviewers will extract the information based on the first 10 publications. Also, during the charting of the information, the reviewers will meet following the extraction of the first 10 studies to make sure that the data extraction follows consistently the purpose of the study. A meeting to evaluate the consistency of the information extracted will allow the reviewers to identify inconsistencies and make decisions regarding the best way to deal with ambiguity.

An iterative process consisting of inter-reviewer discussions held at the beginning, in the middle and at the end of the extraction will lead to a consensus regarding the best way to extract the data. When disagreements persist, a third independent reviewer will be consulted.

Step 5. Data synthesis

This phase involves collating, summarizing, and reporting the results. Compared to systematic reviews, scoping studies present a narrative account of a potentially large body of material [35]. Thus, guided by the previous theoretical frameworks, we intend to identify a descriptive numerical summary (e.g., characteristics of included studies, types of study design, characteristics of the study population, geographical location) and emerging themes (deductive thematic analysis) [57]. Using as an analytical framework the Maslow's hierarchical model of human needs, we will extract the main themes corresponding to the five categories of human needs and classify them as described by professionals, family caregivers, and individuals with SCI. Similarly, met and unmet SCI needs will be classified based on the Ferrans et al.'s model of HRQoL as characteristics of the individual and characteristics of the environment, and their relationship with other components (e.g., biological function, symptoms, functional status, general health perceptions, and overall quality of life). We will create a matrix that integrates the themes identified for the Maslow's and Ferrans et al.'s model that will allow us to explore the relationship between personal and environmental factors (Ferrans et al.'s model) that influence needs (Maslow model). The matrix will allow the identification and intergroup comparison of the met/unmet needs for each one of the groups (e.g., adults with traumatic and non traumatic SCI, their family caregivers, and their rehabilitation professionals). Following the thematic analysis, special considerations regarding the implications for research, policy and practice will be presented. Thus, the analysis will include both individual and environmental influences of quality of life because SCI needs can be unmet at different points of the continuum of care as a consequence of subjective (e.g.,

motivation, believes, and attitudes) and environmental barriers (e.g., administrative issues, financial limitations, limitations of health policies, among others).

Step 6: Stakeholder consultation

The objective of this stage is to start translating knowledge into practice by disseminating results among potential knowledge users. Given the extensive information that will be synthesised and the diverse perspectives involved, we will request input from stakeholders at each step, and for each document/process that is developed for data extraction and synthesis. Therefore, stakeholder consultations will be held at the beginning of the process (requesting feedback to refine the research question, further refine the Ferrans et al.'s model relative to Maslow's model to focus data extraction and synthesis), during the study (validate the data extraction, decide the best way to align the information with stakeholders' needs), two to three times during data synthesis, and when preliminary or final results are available (knowledge mobilisation). Having information about SCI met and unmet needs will help stakeholders to prioritize different needs, based on the conclusions of the scoping review. Thus, stakeholders will benefit from the results and will be able to focus their efforts based on informed decisions about the different SCI needs. The current scoping review will permit to write an integrated master report combining the needs of individuals with SCI from the perspectives of different stakeholders across the continuum of care. However, our knowledge translation plan will include extracting end-user specific information from the master report for each targeted group (i.e., adults with traumatic and non traumatic SCI, their family caregivers, and their rehabilitation professionals). For the current scoping study, relevant stakeholders include support groups of individuals with SCI and their family caregivers, clinicians, and decision-makers. The meetings will be organized either in a face-to-face format or using videoconference to allow broader participation, giving equal representation to the different groups.

Discussion

The current scoping study will answer the question about the most frequent met and unmet needs reported by adults with traumatic and non traumatic SCI, their family caregivers, and their rehabilitation professionals across the continuum of care. The results of the current scoping study could have implications from different viewpoints: a) rehabilitation can be informed from the synthesis of SCI needs because clinicians can become more sensitive as they increase awareness about the complexity of SCI expressed and unmet needs across the continuum of care, b) service provision could be modified from gaining understanding about the gap between unmet and expressed needs, c) the view of rehabilitation as a changing process with evolving needs in different phases of care can help clinicians to understand and modify their practice when considering SCI needs as dynamic in different stages of care, d) the conception of new studies can be informed based on our comprehensive picture of SCI needs as it will suggest priorities in the research agenda, e) the development of new interventions could benefit from our conclusions as they will provide information to help to make informed decisions to address the most important unmet needs as outcomes, and f) policy makers could benefit from these results as they will be able to implement modifications to existent programs to adjust to the complexities of the interactions among different stakeholders involved in the provision of services to increase SCI needs satisfaction.

Scoping studies have some methodological limitations that include the fact that the quality of the evidence is not appraised. Compared to systematic reviews where the quality appraisal and the relative weight of evidence in favour or against a specific intervention is very important, scoping studies are descriptive and narrative [35]. However, scoping studies provide valid specific research questions needing a systematic review through a careful process of scrutinizing evidence coming from different methodologies and study designs. Also, scoping studies are not a short summary of many articles and,

as such, they use frameworks or themes to articulate their findings [57]. For the current scoping study, the theoretical frameworks guiding the analysis of the information have been carefully chosen and weighted against other competing models. However, we are aware that the findings could be interpreted using alternative analytical frameworks.

A few limitations regarding the search strategy need to be acknowledged. The search strategy includes the use of different keywords to address needs, SCI, and the three groups of stakeholders that we would like to target (e.g., individuals with SCI, their family caregivers, and their rehabilitation professionals). However, even when we have clearly widened the keywords, it is possible that alterative terms could make that some of the peer-reviewed literature could not be captured. To overcome this limitation, we have the support of an experienced librarian in health sciences; iterative discussions led to the refinement of the search strategy to avoid missing important pieces of information that could be vital to respond to the research question. At the same time, the search strategy has been keenly refined to avoid having an unmanageable number of references. In addition, scoping studies involve practical issues related to time, funding, and access to resources that must be considered when finding the balance between feasibility, breadth, and comprehensiveness [57].

Issues associated with the resource implications represent the fact that even if scoping studies provide a rapid appraisal and mapping of a specific field, it is wrong to assume that they are a quick or cheap option, with some cases reporting the full-time involvement of at least three staff members and the librarian for six consecutive months, with the study protocol as the starting point [35]. Thus, these studies involve costs regarding the staff involved, the informatics resources needed, and the time demanded in the selection of the studies by staff with the scientific qualifications required to critically select the information and optimally chart the data. For the current scoping study, the experience of our lab in this kind of studies, as well as the scientific qualifications of our staff (e.g., healthcare professionals,

graduate students, postdoctoral fellows, and researchers), make it feasible considering the high levels of analytic skills needed.

In conclusion, this study protocol presents the rationale and methodology for a scoping study on SCI needs. Through a rigorous and transparent method, engaging individuals with SCI, family caregivers, and health professionals at each step, it will provide a framework to understand the most frequent met and unmet needs as reported by adults with traumatic and non traumatic SCI, their family caregivers, and their rehabilitation professionals across the continuum of care.

a. Contributorship statement: Alexander Moreno, Ph.D (conception and design, preliminary literature review, drafting of the manuscript, integrations of the edits in the different versions, and manuscript submission), Diana Zidarov, Ph.D. (edits and feedback), Chandana Raju M.S. (edits and feedback), Jill Boruff, MLIS, AHIP (database search), Sara Ahmed, Ph.D. (conception and design, edits and feedback).

b. Competing interests: None

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d. Data sharing statement: N/A

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Figure legends

Figure 1. Maslow's hierarchy model of human needs

Figure 2. Integrative approach towards SCI needs

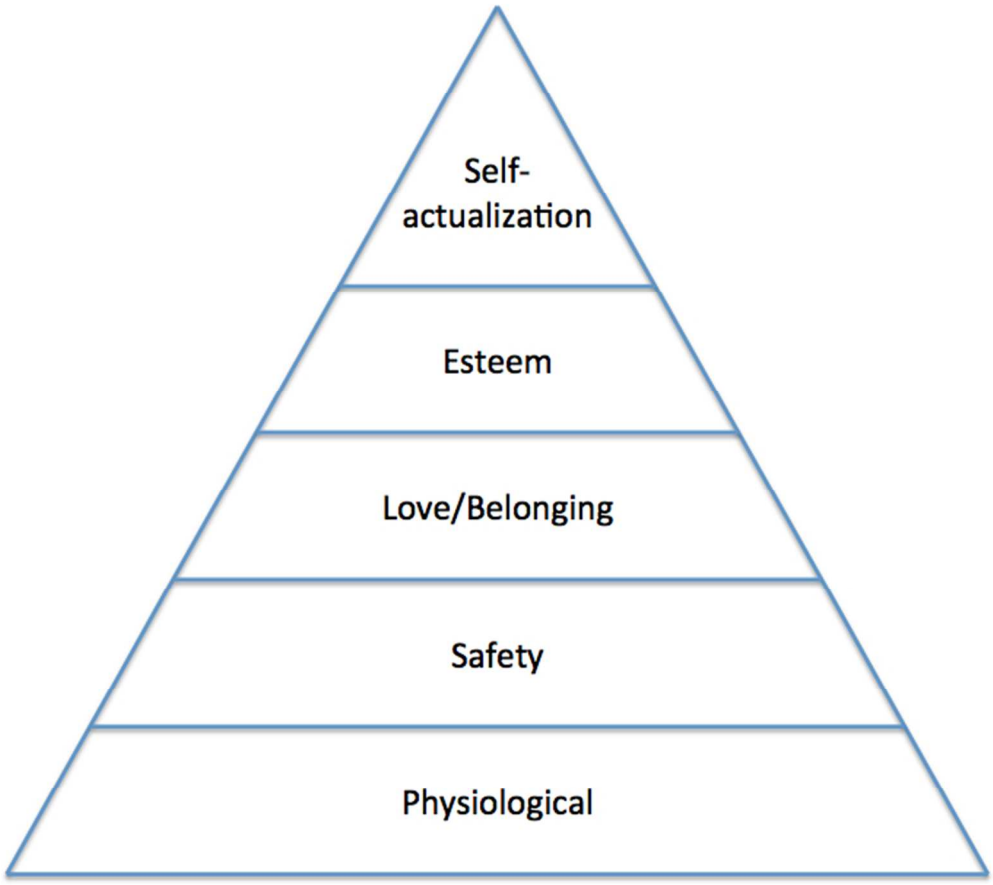

Figure 1. Maslow's hierarchy model of human needs

242x215mm (72 x 72 DPI)

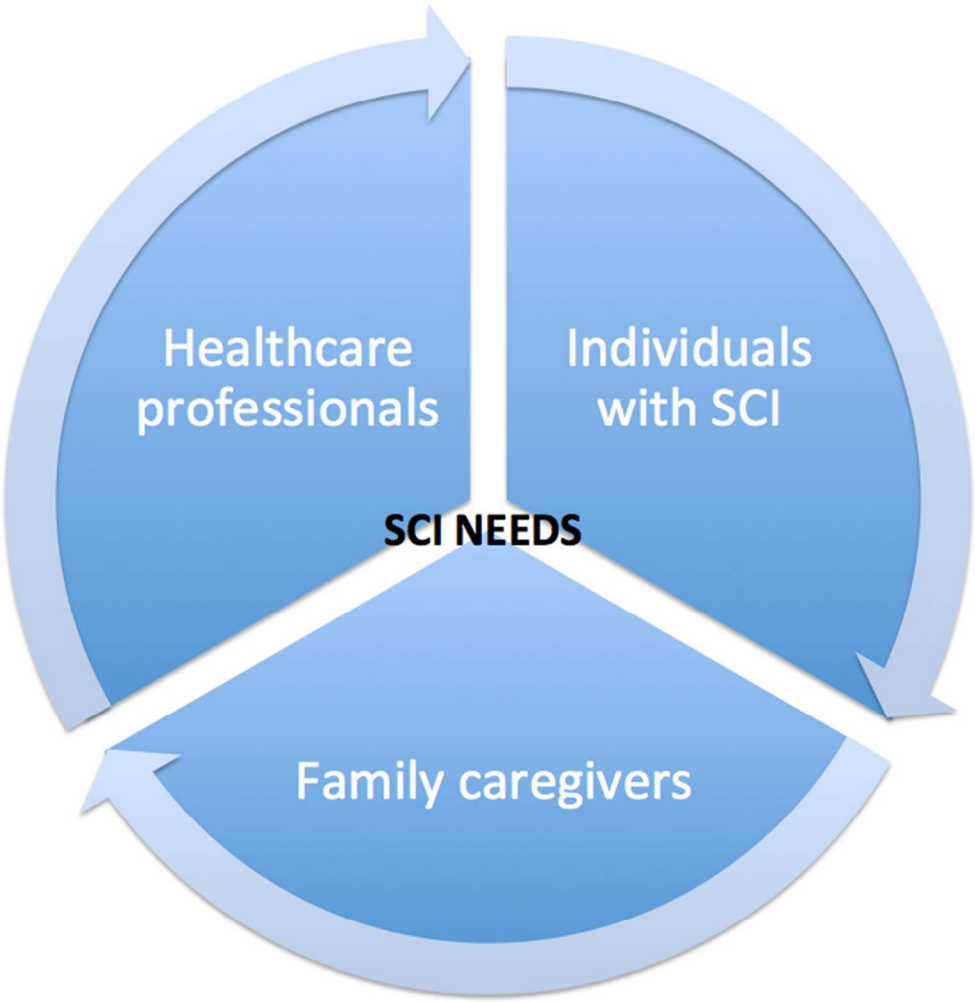

Figure 2. Integrative approach towards SCI needs

252x258mm (72 x 72 DPI)

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Integrating the perspectives of individuals with spinal cord injuries, their family caregivers, and healthcare professionals across the continuum of care: protocol for a scoping study on SCI needs

PRISMA-P (Preferred Reporting Items for Systematic review and Meta-Analysis Protocols) 2015 checklist: recommended items to address in a systematic review protocol*

Reported on page	Section and topic	Item No	Checklist item
	ADMINISTRATIVE INFORMATION		
1	Title		Integrating the perspectives of individuals with spinal cord injuries, their family caregivers, and healthcare professionals across the continuum of care: protocol for a scoping study on SCI needs
1, 4, 13	Identification	1a	Identify the report as a protocol of a systematic review
-	Update	1b	If the protocol is for an update of a previous systematic review, identify as such
-	Registration	2	If registered, provide the name of the registry (such as PROSPERO) and registration number
	Authors		Alexander Moreno, Diana Zidarov, Chandhana Raju, Jill Boruff & Sara Ahmed
1, 2	Contact	3a	Provide name, institutional affiliation, e-mail address of all protocol authors; provide physical mailing address of corresponding author
21	Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review
-	Amendments	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments
	Support:		
3, 21	Sources	5a	Indicate sources of financial or other support for the review
3, 21	Sponsor	5b	Provide name for the review funder and/or sponsor
3, 21	Role of sponsor or funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol
	INTRODUCTION		
6-10	Rationale	6	Describe the rationale for the review in the context of what is already known
10, 13	Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)
	METHODS		
13, 14	Eligibility criteria	8	Specify the study characteristics (such as PICO, study design, setting, time frame) and report characteristics (such as years considered, language, publication status) to be used as criteria for

			eligibility for the review
14	Information sources	9	Describe all intended information sources (such as electronic databases, contact with study authors, trial registers or other grey literature sources) with planned dates of coverage
14, 15	Search strategy	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated
	Study records:		
15, 16	Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review
16, 17	Selection process	11b	State the process that will be used for selecting studies (such as two independent reviewers) through each phase of the review (that is, screening, eligibility and inclusion in meta-analysis)
16, 17	Data collection process	11c	Describe planned method of extracting data from reports (such as piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators
14, 15	Data items	12	List and define all variables for which data will be sought (such as PICO items, funding sources), any pre-planned data assumptions and simplifications
18-20	Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale
18-20	Risk of bias in individual studies	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis
17	Data synthesis	15a	Describe criteria under which study data will be quantitatively synthesised
17		15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data and methods of combining data from studies, including any planned exploration of consistency (such as I^2, Kendall's τ)
17		15c	Describe any proposed additional analyses (such as sensitivity or subgroup analyses, meta-regression)
17		15d	If quantitative synthesis is not appropriate, describe the type of summary planned
-	Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (such as publication bias across studies, selective reporting within studies)
-	Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (such as GRADE)

* It is strongly recommended that this checklist be read in conjunction with the PRISMA-P Explanation and Elaboration (cite when available) for important clarification on the items. Amendments to a review protocol should be tracked and dated.

From: Shamseer L, Moher D, Clarke M, Ghersi D, Liberati A, Petticrew M, Shekelle P, Stewart L, PRISMA-P Group. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation. BMJ. 2015 Jan 2;349(jan02 1):g7647.

BMJ Open

Integrating the perspectives of individuals with spinal cord injuries, their family caregivers, and healthcare professionals from the time of rehabilitation admission to community reintegration: protocol for a scoping study on SCI needs

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Primary Subject Heading:	Neurology
Secondary Subject Heading:	Neurology
Keywords:	Spinal cord injury, Needs, Caregiver, Healthcare, Scoping study

Integrating the perspectives of individuals with spinal cord injuries, their family caregivers, and healthcare professionals from the time of rehabilitation admission to community reintegration: protocol for a scoping study on SCI needs

Alexander Moreno[1, 2], Diana Zidarov[1, 2], Chandhana Raju[1, 2], Jill Boruff[3] & Sara Ahmed[1, 2]

[1]Faculty of Medicine, School of Physical and Occupational Therapy, McGill University, CANADA

[2]Center for Interdisciplinary Research in Rehabilitation of Greater Montreal, CANADA

[3]Schulich Library of Science and Engineering, McGill University, CANADA

Address for correspondence:

Sara Ahmed, Ph.D.

Center for Interdisciplinary Research in Rehabilitation (CRIR) – Constance-Lethbridge Rehabilitation Centre, CIUSSS Centre-Ouest-de-l'Île-de-Montréal, 7005, Maisonneuve Blvd. West, Room 2-335

Email: sara.ahmed@mcgill.ca

Institutional addresses and emails:

Alexander Moreno, Ph.D.: Faculté des sciences humaines, Département de sexologie, Université du Québec à Montréal (UQÀM), C.P. 8888, Succ. Centre-Ville, Montréal, Québec, Canada, H3C-3P8. Center for Interdisciplinary Research in Rehabilitation (CRIR) – Constance-Lethbridge Rehabilitation Centre, CIUSSS Centre-Ouest-de-l'Île-de-Montréal, 7005, Maisonneuve Blvd. West, Room 2-335. Email: moreno.jhon_alexander@uqam.ca ; jhon.moreno@mail.mcgill.ca

Diana Zidarov, pht, Ph.D. Faculty of Medicine, School of Physical and Occupational Therapy, McGill University, 3654 Prom. Sir William Osler, Montreal, Quebec, Canada; Center for Interdisciplinary Research in Rehabilitation (CRIR) – Constance-Lethbridge Rehabilitation Centre, CIUSSS Centre-Ouest-de-l'Île-de-Montréal, 7005, Maisonneuve blvd West, Room 2-335 Email: diana.zidarov@mail.mcgill.ca

Chandhana Raju, B.S.: Constance-Lethbridge Rehabilitation Centre, CIUSSS Centre-Ouest-de-l'Île-de-Montréal, 7005, Maisonneuve Blvd. West, Room 2-335. Email: chandhana.raju@mail.mcgill.ca

Jill Boruff, M.L.I.S.: Schulich Library of Science and Engineering, Macdonald-Stewart Library Building 809 Sherbrooke Street West, Montreal, Quebec H3A 0C1. Email: jill.boruff@mcgill.ca

Sara Ahmed, Ph.D.: Center for Interdisciplinary Research in Rehabilitation (CRIR) – Constance-Lethbridge Rehabilitation Centre, CIUSSS Centre-Ouest-de-l'Île-de-Montréal, Institut de réadaptation Gingras-Lindsay-de-Montréal du CIUSSS du Centre-Est-de-l'Ile-de-Montréal, 7005, Maisonneuve blvd West, Room 2-335; Faculty of Medicine, School of Physical & Occupational Therapy, McGill

University. 3654 Prom Sir-William-Osler, Montreal, QC, Canada, H3G 1Y5; McGill University Health Center, Clinical Epidemiology, 687 Pine Ave W, Montreal, QC, Canada, H3A 1A1

Email: sara.ahmed@mcgill.ca

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Abstract

Introduction: There is fragmented information about the different needs following a spinal cord injury (SCI). Expressed SCI needs can be met or unmet, they change along the rehabilitation continuum (e.g., acute, rehabilitation, and reintegration into the community), and can be different for traumatic and non traumatic SCI. The general objective of this scoping study is to evaluate and integrate the needs of individuals with traumatic and non traumatic SCI, their family caregivers, and those reported by rehabilitation professionals from the time of rehabilitation admission to community reintegration. The specific objectives are to: a) synthesize the needs of individuals with SCI as perceived by themselves, their family caregivers, and rehabilitation professionals using two theoretical models, b) classify needs as met and unmet, c) explore the evolution of met/unmet needs from the time of rehabilitation admission to community reintegration, and d) provide recommendations to improve SCI care.

Methods and analysis: a) identifying the most frequent met and unmet needs reported by adults with traumatic and non traumatic SCI, their family caregivers, and their rehabilitation professionals from the time of rehabilitation admission to community reintegration; b) identifying relevant studies with a search in electronic databases; c) charting the data based on categories refined and adjusted with a stakeholder group; d) collating, summarizing, and reporting the results two analytical frameworks (Maslow's hierarchical model of human needs and the Ferrans et al.'s model of Health-Related Quality of Life), and e) a stakeholder consultation phase.

Ethics and dissemination: The results of this scoping study will allow understanding SCI needs from the time of rehabilitation admission to community reintegration from the perspective of different stakeholders. An integrated master report combining the needs of individuals with SCI from the

perspectives of different stakeholders from the time of rehabilitation admission to community reintegration will follow the consultation meetings.

Keywords: Spinal Cord Injury, needs, caregiver, healthcare, scoping study.

Strengths and limitations of this study

Strengths

- Description of SCI met and unmet needs in different moments of the rehabilitation process.
- Comprehensive definition of needs in the context of SCI.
- Multiperspective approach including family caregivers, healthcare professionals, and individuals with SCI.
- Synthesis of SCI needs using two theoretical frameworks to capture both personal and environmental variables.
- Knowledge translation plan to inform stakeholders about the conclusions.

Limitations

- Scoping studies do not appraise the quality of the evidence.
- Generalization is limited to the SCI population.
- Studies in languages other than English are excluded.

Introduction

Spinal Cord Injury (SCI) corresponds to a neurological condition affecting 330 to 400 per 100,000 Canadians living in the community [1]. According to provincial data, traumatic SCI affects mainly young and middle-aged adults, with men showing the highest prevalence regardless of age group (men-to-women ratio of 4.4:1) [2]. Traumatic SCI is concentrated in younger populations, while non traumatic SCI is condensed in older age groups [3]. In addition, Canadian estimates indicate that compared to non traumatic SCI (49%), the prevalence is higher for traumatic SCI (51%) [3]. Furthermore, SCI is a high-cost chronic disability [4] involving changes in roles, self-image, body function, social interactions, and family relationships [5].

For individuals with SCI, the injury permanently transforms their lives. Indeed, SCI can result in diverse motor, sensory, and autonomic problems [6]. Mobility impairment (e.g., paraplegia, tetraplegia), bowel and bladder incontinence, loss of sensation, and sexual dysfunction are common following SCI [7]. As a result, individuals with SCI have complex health needs as their condition includes chronic multimorbidity, mainly associated with the development of several secondary health conditions (e.g., pain and pressure ulcers) [7]. In addition, compared to community estimates, higher rates of psychological disorders can be present in 17 to 25% of individuals with SCI [8]. Particularly, between 18-37% of individuals with SCI experience depression [9 10].

Also, studies regarding long-term outcomes indicate that individuals with SCI have low employment rates 20 years post-injury [11]. A review shows that employment rates following SCI range from 11 to 69% depending on the definition of employment and differences in the study methodology [12]. Thus, SCI has an important functional, psychological, and social impact on individuals that requires an integrated care approach across the continuum from acute care to community living. For instance,

Craven et al. (2012) stressed the need for lifetime access to rehabilitation healthcare for individuals with SCI [13]. Individuals with SCI require follow-up to address their evolving health needs, including the challenges that represent aging with a disability and the development of SCI-related secondary health conditions.

For families, the unforeseen nature of the injury leads some of the members into an "unexpected career" as family caregivers [14]. As family caregivers normally do not have training for the caregiving tasks (e.g., bathing, dressing, feeding), they can experience role transitions [15], strain [16], isolation [7], burden [17], poor leisure satisfaction [18], reduced ability to become and remain employed [19], and marital disruption [20].

Different perspectives in SCI needs

Individuals with SCI and their families, as well as healthcare professionals must work together to effectively meet the diverse post-SCI needs [21]. For rehabilitation professionals, understanding the interplay of different factors influencing support mechanisms to assist the transition to home and community after discharge can facilitate social reintegration of the individual with SCI [22]. In fact, rehabilitation professionals have an understanding of the needs and barriers that individuals with SCI can encounter. Their observations are valuable as experts due to their professional roles with good knowledge about the problems that individuals with SCI face [23]. Also, they can directly contribute to the understanding of the rehabilitation process and the pre- and post-discharge challenges during service delivery. For instance, shorter lengths of stay during inpatient rehabilitation can diminish the opportunities to provide information and efficiently train dyads of individuals with SCI and their family caregivers when they return to the community [22]. Thus, the healthcare professional's perspective is necessary when depicting a thorough picture of the barriers to meet the needs of individuals with SCI. For instance, a study showed that compared to physiotherapists, some individuals with SCI have unrealistically high expectations about walking one year post-injury [24]. Another study showed that

when the perspectives of individuals with SCI are acknowledged during rehabilitation, they become more committed to therapy, they express more confidence in their treating clinicians, and have better satisfaction and outcomes [25].

Compared to family caregivers of different neurological conditions, family caregivers of individuals with SCI have experienced more frequent physical distress and present increased odds of coronary heart disease and obesity [26]. Thus, their experience as family caregivers is crucial to understand the needs of individuals with SCI, as they progressively become experts by experience while providing care, supporting and addressing the needs of the care recipient with SCI. Family caregivers are an important resource in the treatment of individuals with SCI considering that the quality of the care they provide matches or exceeds the quality of professional care [27]. But unmet caregiver needs may prevent optimal care and negatively affect the health of both the care recipients and their own. From a clinical perspective, understanding the needs of individuals with SCI, knowing the person, and working with the family can be beneficial to guide their healthcare and improve outcomes [28]. As unmet needs have a direct relationship with diminished quality of life [29], it is mandatory to understand them and to find ways to meet them. In consequence, obtaining a comprehensive picture of needs by integrating the different perspectives of professionals, family caregivers, and individuals with SCI is paramount.

Changing needs in the rehabilitation continuum

The challenge is in understanding the evolution of these needs as they change over time. The literature on SCI needs indicates that in the first year post-discharge, the fulfillment of critical needs (e.g., housing, transportation) is below 60% [30], while the long-term care needed is higher than the care received for information and psychosocial care needs [31]. Further, there are differences in needs between individuals with traumatic and non-traumatic SCI. Compared to individuals with non traumatic SCI (>70%), individuals with traumatic SCI (>85%) report more expressed needs on equipment and

technical aids, short-distance transportation, accessible housing, general healthcare, and SCI-specialized healthcare [29]. In addition, individuals with non traumatic SCI report more unmet needs in accessible housing, job training, and peer support [32]. Finally, fully addressing the needs of individuals' with SCI must include evaluating and targeting the needs of family caregivers. Family caregivers of individuals with SCI report health information needs as the most important and emotional support needs as those most often unmet [33]. Among the health and social consequences of unmet needs, individuals with SCI can present higher rates of multimordidity [7 34], dissatisfaction with their lives, high rates of psychological problems [9], poor quality of life [29] and poor long-term integration into the community [30]. Also, unmet needs lead their family caregivers to invest more hours in their care [27].

Gaps in understanding met and unmet needs

Previous studies have evaluated SCI needs separately at different points of the rehabilitation continuum (e.g., inpatient, outpatient, and community) and with different types of SCI (e.g., traumatic versus non traumatic SCI, complete versus incomplete), from the perspective of individuals with SCI, family caregivers, and healthcare professionals. Further, studies have mainly considered SCI needs from a health services perspective rather than from a patient-centered perspective that accounts for areas that influence needs outside of the health system. To our knowledge there are no previous studies that have evaluated the variations in factors and synthesising these needs together from a patient-centered perspective. With fragmented information, it remains difficult for patients, family caregivers, health professionals, and researchers to understand the current gaps in SCI care and the most efficient ways to deliver care that are most likely to address unmet needs.

The objective of this study is to review the literature on SCI needs using a scoping study approach given the diffuse literature on SCI needs. Scoping studies allow for an appraisal of the literature and have four objectives [35]: a) to examine the extent, range, and nature of the research activity, b) to

determine the value of conducting a systematic review, c) to summarize and disseminate research findings, and d) to identify gaps in the literature. This methodological strategy was chosen because compared to systematic reviews, scoping studies address broader topics and questions where different study designs are used, they intend to rapidly map the key concepts of a research area, and they encompass a comprehensive coverage of the literature (breadth more than in-depth). This scoping study will provide broad understanding and synthesis of SCI needs as reported by different stakeholders, for traumatic and non-traumatic SCI, from the time of rehabilitation admission to community reintegration. This scoping study will help us to identify unexplored areas of SCI needs and to provide recommendations to improve the quality of health services, to inform the development of new interventions to address unmet needs.

Theoretical frameworks to guide the evaluation of unmet needs

SCI needs will be synthesised based on two guiding theoretical frameworks: a) the conceptual framework of Maslow's *hierarchy model of needs* coming from humanistic psychology [36] and the Ferrans et al.'s model of Health-Related Quality of Life (HRQoL), which is a modified version of the Wilson and Cleary model of HRQoL [37]. Both the Maslow's model and the Ferrans et al.'s model are informative and appropriate to frame SCI needs taking into account the perspectives of different stakeholders.

The definition of needs has been variable across published studies. Some of them define needs as the discrepancies between what is desired or optimal based on a guideline, and what is actually occurring [38], a circumstance requiring a course of action [39], or services that are necessary to support individual's community living [29]. For the current scoping study, a broader definition of needs corresponds to a lack of something that is essential to a person's existence or well-being, according to Maslow's hierarchical model [40]. In his groundbreaking theory of motivation, Maslow describes human needs as being

hierarchical. Figure 1 depicts the pyramidal representation of human needs. As described in his theory, human needs can be classified in five levels: a) physiological needs, b) safety and security needs, c) belonging and love needs, d) esteem needs, and e) self-actualization needs. In healthcare, the hierarchical model of needs has been applied to nursing [41], geriatric care [42], intensive care [43], palliative care [44], disability and rehabilitation [45], as well as to specific conditions such as dementia [46], type 1 diabetes [47], addiction [48], homeless adults with serious mental illness [49], and dissociative and conversion disorders [50]. Although some of these needs cannot be provided by the health system, the use of this framework has been useful to prioritize, conceptualize and understand needs, to develop a more humanistic approach to successful healthcare, to support person-centered care planning, and to redefine, change and improve the culture of care.

Given that a SCI impacts all domains of the person's life (physical, social, psychological), needs are not only related to the characteristics of the individual but also the environment the person lives in. Therefore the Ferrans et al's model of HRQoL complements Maslow's model as it provides a guide for understanding characteristics of the individual (that are mainly encompassed in the hierarchy model of needs), but also the environmental component (e.g., physical and social environment), as well as health-related domains that influence general health perceptions and quality of life (e.g., symptoms, function, and participation) that need to be addressed when making evidence-based recommendations regarding unmet SCI needs [51]. Thus, both theoretical models will provide an understanding of the dynamics between the motivational aspects associated with SCI-needs (Maslow) and the environmental influences on the HRQoL of individuals with SCI (Ferrans et al.), given that unmet needs have a direct relationship with diminished quality of life [29].

Figure 1. Maslow's hierarchy model of human needs

Insert Figure 1 here

In summary, as studies about SCI needs are conducted in different points of the rehabilitation continuum (e.g., inpatient, outpatient, and community) and with different types of injuries (e.g., traumatic versus non traumatic SCI, complete versus incomplete), a scoping study approach integrating the different perspectives of healthcare professionals, family caregivers, and individuals with SCI, guided by the Maslow and the Ferrans et al's models can help to depict a comprehensive picture of their needs. SCI needs are ongoing and they change in the rehabilitation continuum over the years [52]. In the very stressful period of the acute phase, SCI needs are not the same because both the families and individuals with SCI need time to adjust to their new reality following the injury, whereas outside the rehabilitation center SCI needs change depending on the path that individuals follow [53]. This scoping study will help to identify research gaps regarding SCI needs from the time of rehabilitation admission to community reintegration and to holistically understand the met and unmet needs to improve healthcare with an integrative approach including different perspectives (see figure 2).

Figure 2. Integrative approach towards SCI needs

Insert Figure 2 here

Methods

The current scoping study will use the methodology described by Arksey and O'Malley (2005) [35] .

Step 1. Identifying the research question

The research question guiding the current scoping study is "Which are the most frequent met and unmet needs (e.g., information needs, home support needs, personal care needs, respite needs, psychological support needs, educational needs, employment needs, sexuality needs, technological needs, telerehabilitation needs, spiritual needs, among others) reported by adults with traumatic and non traumatic SCI, their family caregivers, and their rehabilitation professionals from the time of rehabilitation admission to community reintegration?"

Specifically, the current scoping study has four objectives:

1. To synthesize the needs of individuals with SCI as perceived by themselves, their family caregivers, and their rehabilitation professionals according to the categories of the hierarchy of human needs and the Ferrans et al.'s model of HRQoL.
2. To classify needs as met and unmet.
3. To explore the evolution of met/unmet needs from the time of rehabilitation admission to community reintegration.
4. To provide recommendations to improve SCI care.

Step 2. Identifying eligible studies

We will search published articles with the following inclusion criteria: a) publications from all health professions, b) describing different needs in both traumatic and non traumatic SCI, c) participants with 18 years of age and older, d) from acute to chronic injuries, e) the timeframe of publication will be limited to the last 20 years (1997 to 2017), f) qualitative, quantitative studies, and case reports, g) available in English language, and h) grey literature defined as any documentary material that is non commercially published such as technical reports, thesis' repositories, materials produced by associations and the industry, government documents, and working papers [54]. We will exclude: a)

conference abstracts, b) articles published in other languages, and c) studies addressing paediatric populations.

Search strategy and information sources

A health science librarian (JB) developed the search strategy for Ovid Medline (Table 1) and had it peer reviewed by another librarian per the PRESS standard [55]. As health system issues often change with models of care delivery, the economic climate, and the environment, we have decided to narrow the scope to the past 20 years (1997 to present). This search strategy will be adapted for subsequent databases. The following databases will be searched with no date or language limits applied: Ovid Medline®, CINAHL, EMBASE, PsycINFO, Cochrane Library, Web of Science, ProQuest Dissertations and Theses. We will do hand searches of the reference lists of the selected articles to ensure that we have not missed any relevant information.

Grey literature will be searched on SCI websites, scientific and professional associations, and also using search engines on the Internet (e.g., Google and Yahoo). When using search engines, we will retain the first 50 results for the analysis given the amount of information available.

Table 1. Search strategy for Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1997 to present

1	exp Spinal Cord Injuries/
2	spinal cord injur*.tw,kf.
3	exp Paraplegia/
4	Quadriplegia/
5	tetraplegia.tw,kf.
6	paraplegia.tw,kf.
7	Quadriplegia.tw,kf.

8	spinal column injur*.tw,kf.
9	central cord injur*.tw,kf.
10	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9
11	((met or unmet or expressed) adj3 (need or needs)).tw,kf.
12	Needs Assessment/
13	"Health Services Needs and Demand"/
14	Patient Preference/
15	Patient Satisfaction/
16	(sexual* adj2 (concern* or satisfaction or need or needs)).tw,kf.
17	((caregiver* or famil* or spouse* or person* or patient* or client* or individual* or user* or research) adj3 (priorities or expectation* or preference* or perspective*)).tw,kf.
18	((self-actualization or self-esteem or esteem or spiritual or belonging or love or physiological or security or caregiver* or famil* or spouse* or transportation or support or social or economic or health or life or telerehabilitation or rehabilitation or rehabilitative or information or economic or emotional or community or home or personal care or respite or psychological or instrumental or safety or health care or healthcare or educational or employment or leisure or housing or technological) adj3 (need or needs)).tw,kf.
19	11 or 12 or 13 or 14 or 15 or 16 or 17 or 18
20	self concept/ or self efficacy/
21	(satisfaction or needs).tw,kf.
22	20 and 21
23	19 or 22
24	10 and 23
25	limit 24 to yr="1997 -Current"

Step 3: Study selection

In the first step, a reference management software (EndNote X7) will be used to merge the results and remove the duplicates before screening the abstracts. Later, a data extraction form will be developed by the research team to screen the abstracts based on the eligibility criteria described in step 2. Two independent reviewers will conduct the selection of abstracts starting with a pilot phase involving the examination of the first 20 titles and abstracts to screen and decide the retention of the abstract based on the inclusion criteria. The results of the independent ratings will be recorded separately using the data extraction form. Inter-rater agreement will be assessed using the kappa statistic [56]. Inter-rater agreement below 75% will lead to a revision and clarification of the eligibility criteria. The process will

be repeated until an agreement of 75% will be reached, which is evidence of excellent agreement. This is important as it is recommended that discussions are being held regarding the challenges and uncertainties related to study selection and to refine the search strategy as needed [57]. Finally, all eligible studies and those classified as unclear (i.e., requiring further information to make a final decision regarding their retention) will be independently reviewed as full-text articles. Inter-rater agreement will be re-assessed using the kappa statistic [56] on a random sample of 10 publications. Disagreements at this stage will be resolved by consensus. In case of persistent disagreement, a third reviewer will be consulted to determine the final inclusion.

Step 4. Data extraction process

The data extracted in the previous step will include the information corresponding to author(s), year of publication, country of origin and context (where the study was conducted), status of publication (e.g., published or grey literature), journal, aims/purpose, study population (individuals with SCI, family caregivers, rehabilitation professionals) and sample size (if applicable), SCI type (traumatic and non traumatic), level(s) of care (acute, primary care, community), time since SCI, methodology/methods (study design, measures), key findings that relate to the scoping study question/s (in terms of met and unmet specific categories of needs). When available, the time for community reintegration will be included and reported in years. At this stage, two independent reviewers will extract the information based on the first 10 publications. Also, during the charting of the information, the reviewers will meet following the extraction of the first 10 studies to make sure that the data extraction follows consistently the purpose of the study. A meeting to evaluate the consistency of the information extracted will allow the reviewers to identify inconsistencies and make decisions regarding the best way to deal with ambiguity.

An iterative process consisting of inter-reviewer discussions held at the beginning, in the middle and at the end of the extraction will lead to a consensus regarding the best way to extract the data. When disagreements persist, a third independent reviewer will be consulted.

Step 5. Data synthesis

This phase involves collating, summarizing, and reporting the results. Compared to systematic reviews, scoping studies present a narrative account of a potentially large body of material [35]. Thus, guided by the previous theoretical frameworks, we intend to identify a descriptive numerical summary (e.g., characteristics of included studies, types of study design, characteristics of the study population, geographical location) and emerging themes (deductive thematic analysis) [57]. Using as an analytical framework the Maslow's hierarchical model of human needs, we will extract the main themes corresponding to the five categories of human needs and classify them as described by professionals, family caregivers, and individuals with SCI. Similarly, met and unmet SCI needs will be classified based on the Ferrans et al.'s model of HRQoL as characteristics of the individual and characteristics of the environment, and their relationship with other components (e.g., biological function, symptoms, functional status, general health perceptions, and overall quality of life). We will create a matrix that integrates the themes identified for the Maslow's and Ferrans et al.'s model that will allow us to explore the relationship between personal and environmental factors (Ferrans et al.'s model) that influence needs (Maslow model). The matrix will allow the identification and intergroup comparison of the met/unmet needs for each one of the groups (e.g., adults with traumatic and non traumatic SCI, their family caregivers, and their rehabilitation professionals). Following the thematic analysis, special considerations regarding the implications for research, policy and practice will be presented. Thus, the analysis will include both individual and environmental influences of quality of life because SCI needs can be unmet at different points of the continuum of care as a consequence of subjective (e.g.,

motivation, believes, and attitudes) and environmental barriers (e.g., administrative issues, financial limitations, limitations of health policies, among others).

Step 6: Stakeholder consultation

The objective of this stage is to start translating knowledge into practice by disseminating results among potential knowledge users. Given the extensive information that will be synthesised and the diverse perspectives involved, we will request input from stakeholders at each step, and for each document/process that is developed for data extraction and synthesis. Therefore, stakeholder consultations will be held at the beginning of the process (requesting feedback to refine the research question, further refine the Ferrans et al.'s model relative to Maslow's model to focus data extraction and synthesis), during the study (validate the data extraction, decide the best way to align the information with stakeholders' needs), two to three times during data synthesis, and when preliminary or final results are available (knowledge mobilisation). Having information about SCI met and unmet needs will help stakeholders to prioritize different needs, based on the conclusions of the scoping review. Thus, stakeholders will benefit from the results and will be able to focus their efforts based on informed decisions about the different SCI needs. The current scoping review will permit to write an integrated master report combining the needs of individuals with SCI from the perspectives of different stakeholders from the time of rehabilitation admission to community reintegration. However, our knowledge translation plan will include extracting end-user specific information from the master report for each targeted group (i.e., adults with traumatic and non traumatic SCI, their family caregivers, and their rehabilitation professionals). For the current scoping study, relevant stakeholders include support groups of individuals with SCI and their family caregivers, clinicians, and decision-makers. The meetings will be organized either in a face-to-face format or using videoconference to allow broader participation, giving equal representation to the different groups.

Discussion

The current scoping study will answer the question about the most frequent met and unmet needs reported by adults with traumatic and non traumatic SCI, their family caregivers, and their rehabilitation professionals from the time of rehabilitation admission to community reintegration. The results of the current scoping study could have implications from different viewpoints: a) rehabilitation can be informed from the synthesis of SCI needs because clinicians can become more sensitive as they increase awareness about the complexity of SCI expressed and unmet needs from the time of rehabilitation admission to community reintegration, b) service provision could be modified from gaining understanding about the gap between unmet and expressed needs, c) the view of rehabilitation as a changing process with evolving needs in different phases of care can help clinicians to understand and modify their practice when considering SCI needs as dynamic in different stages of care, d) the conception of new studies can be informed based on our comprehensive picture of SCI needs as it will suggest priorities in the research agenda, e) the development of new interventions could benefit from our conclusions as they will provide information to help to make informed decisions to address the most important unmet needs as outcomes, and f) policy makers could benefit from these results as they will be able to implement modifications to existent programs to adjust to the complexities of the interactions among different stakeholders involved in the provision of services to increase SCI needs satisfaction.

Scoping studies have some methodological limitations that include the fact that the quality of the evidence is not appraised. Compared to systematic reviews where the quality appraisal and the relative weight of evidence in favour or against a specific intervention is very important, scoping studies are descriptive and narrative [35]. However, scoping studies provide valid specific research questions needing a systematic review through a careful process of scrutinizing evidence coming from different

methodologies and study designs. Also, scoping studies are not a short summary of many articles and, as such, they use frameworks or themes to articulate their findings [57]. For the current scoping study, the theoretical frameworks guiding the analysis of the information have been carefully chosen and weighted against other competing models. However, we are aware that the findings could be interpreted using alternative analytical frameworks.

A few limitations regarding the search strategy need to be acknowledged. The search strategy includes the use of different keywords to address needs, SCI, and the three groups of stakeholders that we would like to target (e.g., individuals with SCI, their family caregivers, and their rehabilitation professionals). However, even when we have clearly widened the keywords, it is possible that alterative terms could make that some of the peer-reviewed literature could not be captured. To overcome this limitation, we have the support of an experienced librarian in health sciences; iterative discussions led to the refinement of the search strategy to avoid missing important pieces of information that could be vital to respond to the research question. At the same time, the search strategy has been keenly refined to avoid having an unmanageable number of references. In addition, scoping studies involve practical issues related to time, funding, and access to resources that must be considered when finding the balance between feasibility, breadth, and comprehensiveness [57].

Issues associated with the resource implications represent the fact that even if scoping studies provide a rapid appraisal and mapping of a specific field, it is wrong to assume that they are a quick or cheap option, with some cases reporting the full-time involvement of at least three staff members and the librarian for six consecutive months, with the study protocol as the starting point [35]. Thus, these studies involve costs regarding the staff involved, the informatics resources needed, and the time demanded in the selection of the studies by staff with the scientific qualifications required to critically select the information and optimally chart the data. For the current scoping study, the experience of our lab in this

kind of studies, as well as the scientific qualifications of our staff (e.g., healthcare professionals, graduate students, postdoctoral fellows, and researchers), make it feasible considering the high levels of analytic skills needed.

In conclusion, this study protocol presents the rationale and methodology for a scoping study on SCI needs. Through a rigorous and transparent method, engaging individuals with SCI, family caregivers, and health professionals at each step, it will provide a framework to understand the most frequent met and unmet needs as reported by adults with traumatic and non traumatic SCI, their family caregivers, and their rehabilitation professionals from the time of rehabilitation admission to community reintegration.

Ethics and dissemination

As a scoping study is an analysis of published materials, it does not require REB approval. However, for the consultation phase, the plan will be submitted for ethics approval and participants' informed consent will be required at this stage. The dissemination of the results of the scoping study will include multiple steps. First, after the consultation meetings, an integrated master report will be available. The report will combine the needs of individuals with SCI from the perspectives of different stakeholders from the time of rehabilitation admission to community reintegration. Second, we will extract end-user specific information from the master report to be used as a knowledge translation strategy. That is, for each group of stakeholders targeted in the review, there will be specific recommendations to be communicated. For the current scoping study, relevant stakeholders include support groups of individuals with SCI and their family caregivers, clinicians, and decision-makers. The recommendations will be transmitted through meetings. Formats for those meetings include either a face-to-face or videoconferences to allow broader participation, giving equal representation to the different groups.

a. Contributorship statement: Alexander Moreno, Ph.D. (conception and design, preliminary literature review, drafting of the manuscript, integrations of the edits in the different versions, and manuscript submission), Diana Zidarov, Ph.D. (edits and feedback), Chandana Raju M.S. (edits and feedback), Jill Boruff, MLIS, AHIP (database search), Sara Ahmed, Ph.D. (conception and design, edits and feedback).

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d. Data sharing statement: N/A

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Figure legends

Figure 1. Maslow's hierarchy model of human needs

Figure 2. Integrative approach towards SCI needs

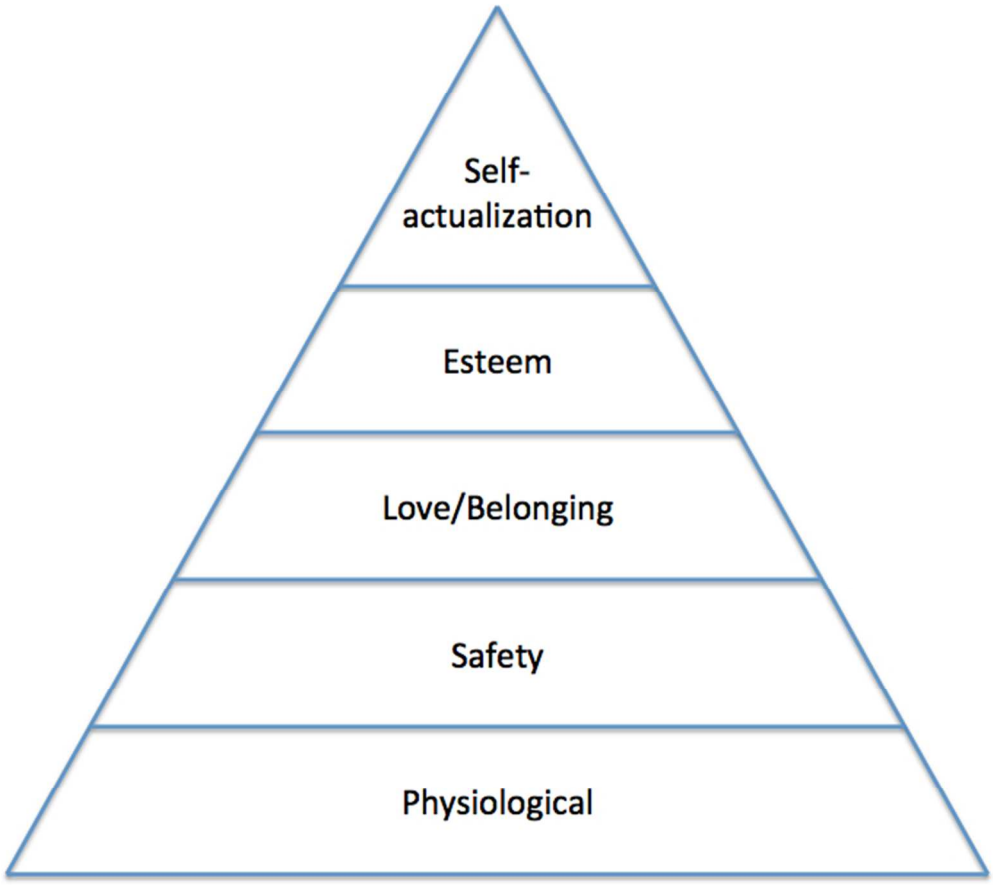

Figure 1. Maslow's hierarchy model of human needs

242x215mm (72 x 72 DPI)

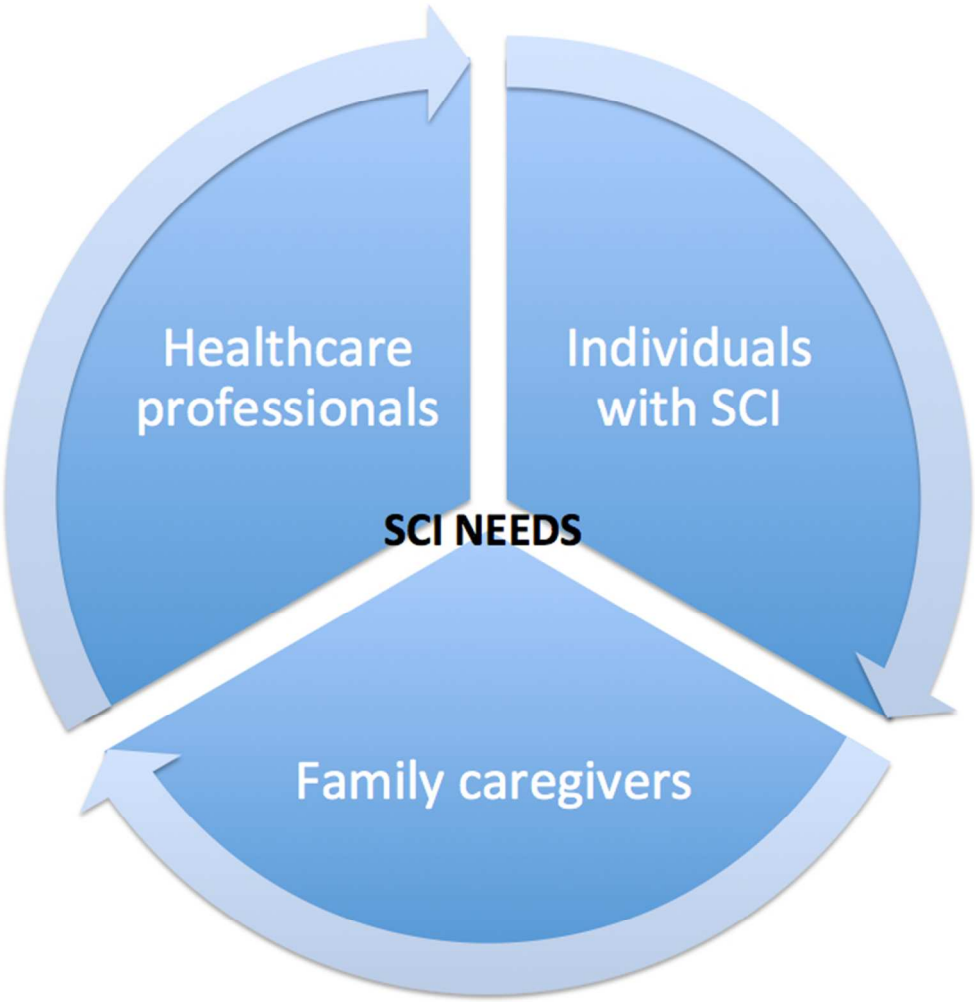

Figure 2. Integrative approach towards SCI needs

252x258mm (72 x 72 DPI)

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Integrating the perspectives of individuals with spinal cord injuries, their family caregivers, and healthcare professionals across the continuum of care: protocol for a scoping study on SCI needs

PRISMA-P (Preferred Reporting Items for Systematic review and Meta-Analysis Protocols) 2015 checklist: recommended items to address in a systematic review protocol*

Reported on page	Section and topic	Item No	Checklist item
	ADMINISTRATIVE INFORMATION		
1	Title		Integrating the perspectives of individuals with spinal cord injuries, their family caregivers, and healthcare professionals across the continuum of care: protocol for a scoping study on SCI needs
1, 4, 13	Identification	1a	Identify the report as a protocol of a systematic review
-	Update	1b	If the protocol is for an update of a previous systematic review, identify as such
-	Registration	2	If registered, provide the name of the registry (such as PROSPERO) and registration number
	Authors		Alexander Moreno, Diana Zidarov, Chandhana Raju, Jill Boruff & Sara Ahmed
1, 2	Contact	3a	Provide name, institutional affiliation, e-mail address of all protocol authors; provide physical mailing address of corresponding author
21	Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review
-	Amendments	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments
	Support:		
3, 21	Sources	5a	Indicate sources of financial or other support for the review
3, 21	Sponsor	5b	Provide name for the review funder and/or sponsor
3, 21	Role of sponsor or funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol
	INTRODUCTION		
6-10	Rationale	6	Describe the rationale for the review in the context of what is already known
10, 13	Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)
	METHODS		
13, 14	Eligibility criteria	8	Specify the study characteristics (such as PICO, study design, setting, time frame) and report characteristics (such as years considered, language, publication status) to be used as criteria for

			eligibility for the review
14	Information sources	9	Describe all intended information sources (such as electronic databases, contact with study authors, trial registers or other grey literature sources) with planned dates of coverage
14, 15	Search strategy	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated
	Study records:		
15, 16	Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review
16, 17	Selection process	11b	State the process that will be used for selecting studies (such as two independent reviewers) through each phase of the review (that is, screening, eligibility and inclusion in meta-analysis)
16, 17	Data collection process	11c	Describe planned method of extracting data from reports (such as piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators
14, 15	Data items	12	List and define all variables for which data will be sought (such as PICO items, funding sources), any pre-planned data assumptions and simplifications
18-20	Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale
18-20	Risk of bias in individual studies	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis
17	Data synthesis	15a	Describe criteria under which study data will be quantitatively synthesised
17		15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data and methods of combining data from studies, including any planned exploration of consistency (such as I^2, Kendall's τ)
17		15c	Describe any proposed additional analyses (such as sensitivity or subgroup analyses, meta-regression)
17		15d	If quantitative synthesis is not appropriate, describe the type of summary planned
-	Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (such as publication bias across studies, selective reporting within studies)
-	Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (such as GRADE)

* It is strongly recommended that this checklist be read in conjunction with the PRISMA-P Explanation and Elaboration (cite when available) for important clarification on the items. Amendments to a review protocol should be tracked and dated.

From: Shamseer L, Moher D, Clarke M, Ghersi D, Liberati A, Petticrew M, Shekelle P, Stewart L, PRISMA-P Group. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation. BMJ. 2015 Jan 2;349(jan02 1):g7647.