Perinatal Care for Women with Spinal Cord Injuries: A Collaborative Workshop for Consensus on Care in Canada

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Background: In North America, there are currently no clearly defined standards of care for women with spinal cord injury (SCI) during the perinatal periods of preconception, pregnancy, labour/delivery, and postpartum. Women with SCI and their partners say resources specific to their needs are hard to find. Little evidence-informed research exists to guide clinicians in the care of women with SCI during pregnancy. **Objectives:** To further explore these gaps in knowledge and practices for perinatal care for women with SCI, a 1-day workshop was held in Vancouver, British Columbia (BC), Canada in November 2013. **Methods:** Twenty-nine attendees included women with SCI, SCI-community service providers, researchers, and health care providers from maternal/fetal medicine, rehabilitation, anesthesiology, and psychiatry. A pre-meeting online survey of stakeholders elucidated 3 themes: lack of knowledge for both consumers and care providers, gaps in access to services and information, and a need for collaboration throughout the perinatal journey. The workshop addressed issues of care providers' lack of knowledge of nonmedical issues during the perinatal period, physical and attitudinal barriers to access to care for women with SCI, and the need for better collaboration and communication between care providers, the latter potentially initiated by providing information to care providers through the women with SCI themselves. **Results:** Content experts attending the workshop collectively made recommendations for knowledge generation and research priorities, clinical application priorities, and the need for policy and guideline development in this field. **Conclusion:** Two information sources for women have since been developed and are available online. **Key words:** Canada, childbirth, obstetrics, perinatal care, pregnancy, spinal cord injuries, women

Women with spinal cord injury (SCI) are choosing to have children. As female fertility is generally unaffected post SCI, many women with SCI are able to conceive, carry, deliver, and care for a baby. Unfortunately, their journey to motherhood can be met with criticism, judgment, and discouragement. Women with SCI face complications unique to each perinatal phase of preconception, pregnancy, labour and delivery, and postpartum,^{1,2} including increased risk for bladder problems, pressure sores, spasticity, and autonomic dysreflexia.³⁻⁶ Health care providers may be unfamiliar with how to manage these medical complications. Women with SCI may

experience social and emotional challenges including attitudinal, educational, socioeconomic, and physical barriers that can lead to inadequate care and compromised health outcomes.⁷ In addition, women with SCI identify the information they receive about pregnancy during rehabilitation as insufficient.⁸

In Canada, it is estimated that there are more than 86,000 people living with SCI⁹; women account for approximately one-third of this population.¹⁰ Data from the Rick Hansen SCI Registry in Canada suggest that there are more than 300 women of childbearing age with traumatic SCI participating in the registry; however, the actual number of

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women in this category with both traumatic and nontraumatic SCI is likely much higher.¹¹

There is limited peer-reviewed research relating to pregnancy and the perinatal journey of women with SCI, although some resources are available online. To better understand gaps in knowledge, priorities for research, and resource development needed within this field, a limited scientific literature review relating to SCI and pregnancy was undertaken, and key stakeholders (including women with SCI themselves) were engaged to understand how to improve perinatal care for women with SCI in British Columbia.

Methods

The project was led by a team comprising 3 nurses (2 sexual health rehabilitation clinicians from Vancouver Coastal Health and 1 nurse specialist in perinatal care at BC Women's Hospital with extensive experience in providing care for women with SCI), a sexual medicine physician, a social worker with an SCI and mother of 2 children, a knowledge translation (KT) specialist, and the executive director of SCI-BC, a nonprofit organization specializing in peer support and information services. The project, which received ethics approval, consisted of 4 primary components: literature review, stakeholder identification, stakeholder survey and modified Delphi process, and workshop.

Literature review

A review of the literature relating to SCI and pregnancy, as well as a broader review covering physical disability and pregnancy, was conducted. The following Medical Subject Headings (MeSH) terms were used in the Cumulative Index of Nursing and Allied Health Literature (CINAHL), MEDLINE, and PsycInfo databases: spinal cord injury* AND prenatal care OR pregnancy OR pregnancy outcome OR childbirth OR perinatal OR obstetrics. It did not include online patient resources. The search included articles from 1988 to 2016. The 3 databases identified articles for review; CINAHL listed 216, MEDLINE found 259, and PsychINFO reported 198. After removing duplicates and reviewing titles and abstracts, 40 articles of relevance were identified.

Stakeholder identification

Relevant stakeholders were identified through a 3-step, iterative process that included identifying stakeholder groups, assigning those groups to positions in the order of the extent to which they could affect or be affected by a challenge or decision,¹² and validating the stakeholder selection with the members of the project team. Identified stakeholders were invited to participate in an online survey and workshop.

Stakeholder survey and modified Delphi process

For the first phase of stakeholder engagement, an online survey (**Appendix A**) was developed by the project team to identify what stakeholders believed to be the key health care-related issues and priorities for women with SCI during the perinatal phases of preconception, pregnancy, labour and delivery, and postpartum.

The survey was distributed online to the 30 identified stakeholders prior to the workshop. Four members of the project team independently reviewed the results to identify recurring themes. Similar or identical responses were collated, multiple concepts within one statement were separated, and the statements were edited for clarity (spelling, grammar, and removal of discipline/agency-specific acronyms). Subgroup analysis was also completed to determine whether the concepts or the related importance ratings varied based on the perspectives of different stakeholder groups. Four members of the project team grouped the responses into themes, which were then further reviewed by the larger project team until consensus on the themes was reached. The results of this survey were compiled for presentation to the stakeholders during the project workshop for validation and expansion of the themes identified.

Workshop

Twenty-nine stakeholders, including some from the survey phase and additional identified professionals, attended a 1-day workshop in Vancouver, British Columbia on November 28, 2013. An experienced external moderator directed the process.

Using the themes identified by the survey as a framework, the intent of the workshop was to share and gather information, identify areas of priority for future research and information resource development, and allow networking among participants from the various disciplines and experiences. The workshop opened with short introductions from each of the participants and stories of personal motherhood experiences by 2 of the SCI consumer participants, which were told through PowerPoint presentations. The remainder of the workshop was facilitated by an independent moderator to achieve consensus on identified themes. The pre-workshop survey findings were then presented and discussed. Workshop participants separated into 4 groups to review and discuss the collated survey themes and to identify where future collaborations could help improve perinatal care of women with SCI. Each group presented back to the larger group, and this was followed by a facilitated discussion of the survey results. A broader conversation regarding future directions and tools for change concluded the workshop.

At the end of the workshop, participants were given a 10-question evaluation form (**Appendix B**) that was developed by the project team. The evaluations were collected that day and were analyzed later by members of the project team. Analysis was done by manually tabulating the written responses into a Word document.

Results

Literature review

The search identified 40 relevant articles, of which 28 were specific to SCI and 12 were related to general disability. In general, women with SCI view pregnancy and birth positively, despite the challenges they face.¹³ However, the review highlighted that women with SCI face a variety of challenges related to pregnancy and perinatal care and support, ranging from a lack of accessibility of physician offices^{7,14-17} to the lack of health care provider education, knowledge, and training about disability and pregnancy.^{7,15-19} Women with SCI felt that they had to educate themselves on the issues related to their condition and pregnancy.¹⁵ Only 9%

of women with SCI feel that the information they received in the rehabilitation setting was effective for preparing them for pregnancy.⁸ Conversely, a collaborative health care team approach prior to a woman becoming pregnant was seen as desirable to assist women in understanding their needs during pregnancy and ensure positive outcomes.²⁰ Pre-pregnancy counseling and a team meeting at the beginning of the second trimester to organize and collaborate care has been recommended.²¹ The literature on SCI and pregnancy further validates the issues related to accessibility²²⁻²⁵ and limited knowledge by health care providers.^{8,22-29} The importance of peer involvement was highlighted as a positive intervention to the psychological challenges women face.^{13,30} Multidisciplinary collaboration can further promote positive outcomes in pregnancy for women with SCI.^{26,30-33}

Only 4 of the papers were Canadian-based, further supporting the need to better understand the Canadian perinatal care experience of women with SCI.

Identification of stakeholders

Identification and engagement of relevant stakeholders in the early stages of this project was important, because those who are directly involved in delivering or receiving services are often in the best position to inform and advance the research process and affect change based on the outcomes of the research.³⁴ The authors undertook a stakeholder analysis in the early stages of this project to ensure rigorous identification and classification of potential stakeholders.¹² This was in keeping with literature that suggests the use of a mixed group of internal and external members to conduct stakeholder analysis.³⁵ Fifty-three different professional groups were identified, and the team agreed on 30 key stakeholders to invite to participate in the pre-survey and workshop.

Survey results

Of the 30 stakeholders identified, 9 were physicians, 4 were consumers, 4 were registered nurses (RNs), 4 were researchers, 2 were physiotherapists (PTs), 1 was a midwife, 1 was a social worker, 1 was an occupational therapist

(OT), 1 was a sexual health educator, 1 was a KT specialist, 1 was a mental health professional, and 1 was a leader of a nonprofit SCI community service organization. All participants were from Canada; 24 of the participants were from British Columbia (BC), 4 were from Ontario, 1 was from Quebec, and 1 was from Saskatchewan.

From the 30 distributed surveys, 19 (63%) completed surveys were received. Twelve (63.2%) of the respondents primarily identified themselves as health care providers, 4 (21.1%) as consumers, and 2 (10.5%) as researchers; 1 (5.3%) respondent chose “other” as the identifier. There was substantial agreement between the different stakeholder groups on the current gaps in knowledge and access to information and services. **Table 1** highlights some concepts from the pre-survey.

Workshop results and evaluation

Of the identified stakeholders, 29 invited attendees participated in the workshop. There were 7 physicians, 7 RNs, 5 consumers, 2 PTs, 2 OTs, 1 mental health professional, 1 social worker, 1 researcher, 1 KT specialist, 1 PhD student, and 1

leader of a nonprofit SCI organization in attendance. Of these participants, all but 1 were from Canada: 24 from BC, 3 from Ontario, and 1 from Saskatchewan. One attendee was from Denmark.

Three themes were identified from the initial survey and ratified at the workshop.

1. A lack of knowledge for both consumers and care providers: This included a paucity of reliable information resources to support women and their care providers; a lack of information beyond urinary tract infection and autonomic dysreflexia; and uncertainty as to why all pregnancies in women with SCI in Canada were identified as high risk. It was identified that targeting the development and provision of information should be the primary focus of future efforts.
2. Gaps in access to services and information: The participants identified gaps relating to geographical disparities in availability and access to services and information; a lack of accessibility of service delivery sites; misconceptions and attitudinal barriers of health care providers; a lack of specialized knowledge in providers; and difficulty

Table 1. Selection of pre-workshop survey concepts

Concepts	Themes
Knowledge	Lack of information and/or access to information by providers
	Raise awareness among health care providers that pregnancy is an option
	Are all SCI pregnancies considered high risk? What type of surveillance would pregnant SCI women need compared to the regular population?
	Increasing awareness of the special considerations for SCI
	Emphasis on the benefits/positive aspects of labour instead of all that can go wrong
Collaboration	Discussions related to postpartum support needs prior to delivery (ie, family support, equipment needs, breastfeeding supports, postpartum depression resources)
	Include women with SCI/lived experience as part of education
	Communication: work together with the woman and her identified labour and delivery team
Access	Access to wheelchair accessible room and equipment during labour and delivery
	Decreasing the fears and stigma about accessing mental health support
Research priorities	Qualitative data about women with SCI in families with kids; positive stories are needed
	Perinatal and postnatal mental health issues with women with SCI
	Prospective and population-based studies; we need more data
Policy change/social reform	Best practice guidelines for all health care professionals to ensure evidence-based interventions.
	More research into breastfeeding and SCI and support around feeding challenges
	Temporary increases in attendant care services during and after pregnancy to assist with activities of daily living

in accessing emotional, psychosocial and financial supports. Access to information (available resources versus resources needed) and access to referrals and community linkages were also identified as barriers to care.

3. A need for collaboration both between the consumer and health care providers and among health care providers throughout the perinatal journey: Despite women with SCI accessing numerous care providers, communication between these professionals is often limited and was described as “fragmented” in the workshop. Both the survey and workshop participants identified that anticipating women’s needs and providing

individualized care and a trusted source of information were the key priorities to address the fragmentation of care. **Figure 1** depicts the important connections and collaborations identified as necessary for women with an SCI during the perinatal phases.

Workshop participants collectively made a recommendation for the development of a pregnancy “roadmap” to guide and empower consumers and health care providers through the perinatal journey. The roadmap will allow consumers and health care providers to determine key information needs and best care practices at each stage of pregnancy, thereby promoting positive outcomes and access to appropriate services for families, regardless of their geography.

Figure 1. The important connections and collaborations necessary for women with a spinal cord injury (SCI) during the perinatal phases. HCP = health care provider.

The project team committed to continue working with the workshop attendees to review the content developed for the roadmap. A summary of the specific recommendations for the roadmap resource and topics for future research from the workshop are listed in **Table 2**.

The evaluation survey distributed at the end of the workshop was completed by 21 of the attendees: Eighty-one percent rated the workshop as “excellent” in meeting their expectations, and the remaining 19% rated the workshop as satisfactory. The workshop evaluation demonstrated that 90% of the respondents felt the workshop had increased their understanding of perinatal care for women with SCI, and 100% agreed that it increased their desire to collaborate in future projects related to this care. Several participants commented that the presentations by the 2 consumer representatives had been compelling and reminded the group of the reason they had come together. Participants also commented positively on the value of collaboration and making connections with other disciplines during the workshop. For example, one participant stated, “It is the connections that were made during the workshop that are invaluable to planning future perinatal care for women with SCI.” The overall consensus of the workshop participants was that the day was one of inspiration and hope for the future.

Discussion

Women with SCI can and often want to have children of their own. Unfortunately, they face a broad set of challenges along their perinatal journey, including physical, attitudinal, and knowledge barriers. It is clear from the results of this stakeholder engagement project that efforts must be made to address identified gaps in knowledge, improve access to information and accessible services, and promote collaboration in care for women with SCI and their families throughout the perinatal period.

Lack of knowledge

The results of the pre-workshop survey and workshop indicate that there is a general lack of knowledge amongst both women with SCI and their health care professionals about the issues related to pregnancy and SCI, and few sources of reliable information to support women and their care providers exist. The information about pregnancy and SCI in the literature trend toward a focus on urinary tract infection and autonomic dysreflexia.^{3,4} Research from Switzerland reports that sufficient self-care can lead to lower complication rates in “high risk” instances when adequate information is provided to women during rehabilitation.³⁶

Table 2. Workshop recommendations for future resource(s) and research

Identified priorities	Resource and research
Information resource for women with SCI	Include: women’s stories and photos; provide links to the information that is common for all pregnant women; provide links specific to the special considerations in pregnancy for women with SCI. This resource could take the form of a checklist or “roadmap” and should be easily accessible online to both women with SCI and their care providers.
Topics for further research	Lactation Deep vein thrombosis (DVT) risk Edema management Orthostatic hypotension Obstructive sleep apnea Heterotrophic ossification Flexion contractures Mode of delivery Medication safety Determinates of high-risk pregnancies and postpartum depression

The workshop participants felt that targeting the development and provision of information to women with SCI should be the primary focus of future knowledge translation and knowledge mobilization initiatives. Likely due to the relatively low prevalence of SCI in the general population, persons with SCI report anecdotally that it is difficult to find primary care providers with specialized knowledge in SCI. As a result, persons with SCI often have to provide information to their physicians about their individual health needs and situation.³⁷ Due to the lack of exposure to disability-related concerns during training and practice, family physicians are unlikely to have the knowledge of the specific considerations for pregnancy for a woman with SCI.²³ Equipping the woman herself with the information is likely the most direct route to reach health care providers as needed.

Access

The theme of access to SCI perinatal care and resources emerged as multidimensional, with the components identified being consistent with previous work in the broader disability community.^{14,38}

With respect to geography, women in rural areas may have limited access to specialized health care professionals and resources as compared to urban centers. Furthermore, resources are limited in urban centres and they lack specialized SCI care services.³⁹ The known discrepancy of accessibility to information and specialized care,^{14,38,39} as well as the need to develop resources that can be used regardless of geographical location, was highlighted in our workshop.

Physical barriers to service delivery sites include nonstandardized wheelchair accessibility in the community and a lack of items such as accessible doorways and beds (ones that lower for transferring) or mechanical or ceiling lifts for women with SCI who are unable to self-transfer.

Attitudinal barriers created by misconceptions, cultural biases of health care providers, and negative societal myths continue to exist for people with disabilities and can influence how they receive care.^{23,40} One of the participants with SCI reported receiving comments from her family

physician such as, “Why would you want to take this [pregnancy] on when you have so much to deal with already?” Furthermore, consumer participants commented that they were hesitant to access care once they had their baby because of the fear of being judged and feeling they had to prove they were a good mother.

Emotional and physical support from SCI peers, family, and health care providers is often difficult to access, as is financial support for the facilities providing care and for adequate equipment at home or in facilities.

Although some credible, online resources exist, the development of reliable and validated information resources for women with SCI and greater collaboration with consumers and health care professionals will be necessary to overcome the barriers of access to information, referrals, and community linkages.

Need for collaboration

Women with SCI access numerous care providers; however, communication between these professionals is often limited. In the workshop, perinatal care for women with SCI was described as “fragmented.” Both the survey and workshop identified that anticipating women’s needs and providing individualized care and a trusted source of information are key priorities to address the fragmentation of care. Having a clear idea of who is responsible for follow-up care postpartum would help increase continuity of care.

Developing linkages through communication with fetal medicine specialists, rehabilitation medicine, and family physicians is a place to start. **Figure 1** illustrates these linkages. Strategies to determine how to continue open communication between these care providers need to be further evaluated.

One limitation of the study was that the majority of stakeholders consulted were living or practicing within BC, because the primary emphasis was to identify the current state of care delivery and practice for women with SCI in BC. However, there was national and international representation among participants, and it is reasonable to assume that the key needs and priorities identified are applicable to women with SCI across Canada and internationally.

Next steps

The project team was hopeful that the connections made within the workshop could be maintained through communications between the project team and the broader group (workshop and survey participants). Therefore, subsequent to the workshop, the project team forged relationships with Perinatal Services of BC, the Society of Obstetricians and Gynecologists of Canada (SOGC), and SCI-BC to reach a wider audience and utilize their consumer and health care professional websites as vehicles for knowledge dissemination. Based on the results of the survey and workshop, the project team developed 2 information resources for women with SCI: an online SCI peer-based experiential video⁴¹ and an information guide for women with SCI contemplating pregnancy and motherhood that is available in print and online.⁴² Future directions will include more knowledge translation activities and research, including an international survey to identify key gaps in knowledge and care in lactation support for women with SCI.

Conclusion

Women with SCI are underrepresented in methodological research and underserved in terms of clear clinical guidelines and evidence-based care in the perinatal phases of preconception, pregnancy, labour and delivery, and postpartum. This work has identified key gaps and needs in the areas of knowledge, access, and collaboration, which are preventing women with SCI from receiving the best possible care during the perinatal phases. Expert stakeholders identified priority areas in research and delivery of care that must now be addressed to allow women with SCI to feel supported and confident in the care they receive as they contemplate and undertake motherhood.

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Appendix A

Survey for Perinatal and Women with SCI

Introduction: The goal of this process is to identify key gaps in knowledge and care for women with Spinal Cord Injury (SCI) during the perinatal phase. The perinatal phase refers to the period of time from when a woman is considering getting pregnant, throughout pregnancy, labour and delivery, and after giving birth. The results of this study will be used to inform future research agendas and make policy recommendations.

From your perspective, as health care consumer, health care provider or researcher, please answer the questions below regarding the perinatal phases for women with SCI (and their families). This survey should take you approximately 20 minutes.

Demographics (choose one option)

Which of the following do you primarily identify as:

- Consumer
- Health care provider
- Researcher
- Other

Pre-Pregnancy Planning

1. What are the key issues/priorities to address in this phase?
2. What barriers do women face in accessing care or information in this area?
3. What learning needs or gaps for health care providers can you identify?
4. What are the research priorities?
5. What would you like to see in policy change/social reforms?

Pregnancy

1. What are the key issues/priorities to address in this phase?
2. What barriers do women face in accessing care or information in this area?
3. What learning needs or gaps for health care providers can you identify?
4. What are the research priorities?
5. What would you like to see in policy change/social reforms?

Labour & Delivery

1. What are the key issues/priorities to address in this phase?
2. What barriers do women face in accessing care or information in this area?
3. What learning needs or gaps for health care providers can you identify?
4. What are the research priorities?
5. What would you like to see in policy change/social reforms?

After Delivery

1. What are the key issues/priorities to address in this phase?
2. What barriers do women face in accessing care or information in this area?
3. What learning needs or gaps for health care providers can you identify?
4. What are the research priorities?
5. What would you like to see in policy change/social reforms?

Appendix B

Perinatal Care for Women with SCI Workshop Evaluation

For multiple choice questions, please check one answer only.

1. Please rate the workshop on the extent to which you felt it met its objectives. The objectives were: to identify key gaps and priorities in knowledge and care for women with SCI in the perinatal phases of pre-pregnancy, pregnancy, labour and delivery, and post-partum:

- Excellent
- Satisfactory
- Unsatisfactory
- Poor
- No answer

2. What were your expectations for the workshop?

3. Please rate this workshop on the extent to which it met your expectations:

- Excellent
- Satisfactory
- Unsatisfactory
- Poor
- No answer

4. Please tell us how much you agree or disagree with the following statements:

The workshop planning was well done (including the pre-workshop survey):

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- No answer

The workshop facilities were comfortable and appropriate:

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- No answer

The workshop facilitation was well done:

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- No answer

5. Please share what you think about the following aspects of the workshop:

The number of participation in this workshop was:

- Too many
- Just the right number
- Too few
- No answer

The length of the workshop sessions were:

- Too long
- Just about right
- Too short
- No answer

6. Has your understanding of perinatal care for women with SCI changed as a result of this workshop?

- Yes
- No

7. Please indicate your level of agreement with the following statement: This workshop has increased my desire to collaborate on improving perinatal care for women with SCI.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- No answer

8. What did you like most about the workshop?

9. What did you like least about the workshop?

10. Do you have any other comments for us?